AN INVESTIGATION OF THE RELATIONSHIPS AMONG MEANING, PSYCHOLOGICAL WELL-BEING AND CAREGIVER BURDEN

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Abstract

Investigation of the Relationships Between Meaning, Psychological Well-Being, and Caregiver Burden

A descriptive, correlational investigation of 45 informal family caregivers of institutionalized Alzheimer care-recipients was conducted to explore relationships between meaning, psychological well-being, caregiver burden. Home interviews were conducted using the following instruments: Life Attitude Profile - Revised (LAP-R), Memorial University of Newfoundland Scale of Happiness (MUNSH), Caregiver Burden Inventory (CBI). A correlational matrix was created, followed by stepwise multiple regression. The results are as follows: (a) length of illness was an influential variable, related to meaning, psychological well-being, caregiver burden; (b) psychological well-being was the only predictor of caregiver burden; and (c) psychological well-being was predicted by: purpose, existential vacuum, age, length of illness, number of visits, and relationship to care-recipient, respectively. Implications for nursing practice, education, and research are discussed.

Dedicated To the memory of my Mother,

Margaret E. Wilson Snow

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Finally, to the subjects in the investigation who allowed me into their homes, I feel privileged and humbled to have shared a part of your experience with you. I hope this investigation will help nurses to further understand the impacts of caregiving.

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CHAPTER I

Problem and Purposes

Introduction

Caregivers are not new to society, but the emerging knowledge of caregiver burden, combined with an increasing elderly population in our society, targets this group of individuals as a high-risk group who are potential users of the health care system (George & Gwyther, 1986; Haley, Brown & Levine, 1987; Haley, Levine, Brown, & Bartolucci, 1987; Katon, Kleinman & Rosen, 1982). The caregiving literature acknowledges caregiver burden as a term widely used to refer "to the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults" (George & Gwyther, 1986, p. 253).

The negative impacts of caregiving are referred to as strain, stress or burden (Barusch & Spaid, 1989; Fiore, Becker & Coppel, 1983; Fittings, Rabins, Lucas & Eastham, 1986; George & Gwyther, 1986; Gilhooly, 1984; Haley, Levine, Brown, & Bartolucci, 1987; Horowitz, 1985; Mace & Rabins, 1981; Novak & Guest, 1989; Robinson, 1983; Robinson, 1989; Smith, Smith & Toseland, 1991; Staight & Harvey, 1990; Townsend, Noelker, Deimling & Bass, 1989; Zarit, Reever & Bach-Peterson 1980). As

well, there is a greater prevalence of depression within the caregiver population (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Haley, Brown, & Levine, 1987; Kinney, & Stephens, 1989b; Lezak, 1978). Positive impacts of caregiving are referred to as uplifts, satisfactions and gratifications experienced when caring for a family member (Gallagher, 1985; Hirschfield, 1981; Horowitz, 1982a; Kinney & Stephens, 1989b; O'Connor, Pollitt, Roth, Brook & Reiss, 1990; Reece, Walz & Hageboeck, 1983; Staight & Harvey 1990). The potential impacts of caregiving may affect the physical and\or psychological well-being of the caregiver (George & Gwyther, 1986; Horowitz, 1985; Kinney & Stephens, 1989b). Psychological well-being of the caregiver is defined as the "presence of positive emotions such as happiness, contentment, joy, peace of mind and the absence of negative emotions such as fear, anxiety, and depression (Reker & Wong, 1984, p. 24). Limited research acknowledges that the burdens or uplifts of caregiving affect both the informal caregiver in the community and the informal caregiver of the institutionalized recipient (Branson, 1976; Hatch & Franken, 1984; Montgomery, 1982; Silverstone, 1978; Silverstone & Burack-Weiss, 1983; Tobin & Kulys, 1981). Novak and Guest (1989) suggest that the reported overall level of burden may be less in the caregiver of the institutionalized patient.

There are also marked individual differences in the degree to which caregivers experience the outcomes of caregiving. This variation in response to the caregiving role is influenced by the meaning that the caregiver attributes to the experience (Bulman & Wortman, 1977; Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991; Haley, Levine, Brown & Bartolucci, 1987; Hirschfield 1983; Kahana, Kahana, Harel & Rosner, 1988; Townsend et al., 1989; Zarit et al., 1980). Most of the literature has divided the caregivers into groups caring for a homogeneous recipient population such as: (a) those with dementia (Chenoweth & Spencer, 1986; George & Gwyther, 1986; Greene, Smith, Gardiner & Timbury, 1982; Haley, Levine, Brown & Bartolucci, 1987; Morris, Morris & Brittan, 1989; O'Connor et al., 1990; Pett, Caserta, Hutton & Lund, 1988; Quayhagen & Quayhagen,1989; Rabins, Mace & Lucas, 1982; Whittick 1989); (b) those with Alzheimer disease (Fiore, Becker & Coppel, 1983; Pagel, Becker & Coppel, 1985); (c) the frail elderly (Cantor, 1983; Horowitz, 1985; Reece et al., 1983; Smith & Bengston, 1979); and (d) the disabled (Fengler & Goodrich 1979; Wilson, 1990). Similarly, the caregivers have been traditionally grouped according to their relationship with the recipient: (a) spouses (Fiore et al., 1983; Morris, Morris & Britton, 1989; Pagel et al., 1985); (b) adult children (Hatch & Franken, 1988; Smith & Bengston, 1979); (c) family, a combination of adult child and spouse (Horowitz &

Shindelman, 1983; Rabins et al., 1982; Reece et al., 1983; Schneewind, 1990; Tobin & Kulys, 1981); and (d) relatives (Greene, Smith, Gardiner & Timbury 1982; Haley, Levine, Brown & Bartolucci, 1987; O'Connor et al., 1990; Pett et al., 1988). It is timely for the caregiving research to acknowledge individual meaning as an influential variable that is reflected in the reported level of caregiver burden. The meaning of caregiving is an individual matter. "It is the caregiver's choice, values and responsibility for right action and conduct that determine whether caregiving will have provisional or ultimate meaning" (Farran et al., 1991, p. 484). A study on the relationship between meaning and caregiver burden will increase the understanding of this particular phenomenon.

Significance of Problem

Alzheimer disease is a chronic, progressive, irreversible dementia, characteristically seen in the elderly (Billig, 1988; Harding, 1990; Howard, 1990). The Diagnostic and Statistical Manual of the American Psychiatric Association (DSM 111R), defines dementia as a global cognitive deterioration, generally characterized by impairments in memory, concentration, orientation, judgements, intellectual functioning, motor skills, and activities of daily living in patients

with a normal level of consciousness (p. 37). The disease is diagnosed by the presentation of symptoms and an elimination of any other causes, as the only conclusive diagnosis can be obtained at a post mortem detecting physical changes in the brain (Alzheimer Society of Canada, 1989).

Canada's population is aging. This is reflected in the considerable changes in the size, composition and distribution of its population (Stones & Fletcher, 1986). The growth rate for the elder population is expected to rise dramatically for the next fifteen years. Consequently, this aggregate will become a numerically larger group of people. This has major implications for the health care system, as the prevalence and incidence of diseases which are characteristically seen in the elderly (i.e. dementia) are expected to rise as well. Prevalence refers to the ratio of diagnosed cases of a disease in the overall population, whereas, incidence refers to the ratio of new cases of a disease in the overall population (Stones & Fletcher, 1986).

An increased prevalence of Alzheimer disease translates into an increased number of informal caregivers (i.e. persons who are unpaid for their services) in society. Therefore, health professionals, especially nurses, will be encountering a greater number of informal caregivers in the course of their careers. As nursing is an applied science, an understanding of the concepts (i.e. caregiver) must be attained before appro-

priate nursing interventions can be formulated to guide patient care. A greater understanding of the caregiving experience would facilitate the nurse's interactions with this group of people, to the benefit of all who are involved such as the nurse, the caregiver and the recipient of care.

Research which enhances knowledge about individual responses to caregiving will provide a valuable foundation for further nursing research and will help to guide nurses in the formulation of appropriate and effective nursing interventions for the caregiver of an Alzheimer patient. Quality of life would be enhanced directly for the caregiver and indirectly for the recipient of care (Fengler & Goodrich, 1979).

In summary, several societal factors influence the importance of expanding the knowledge base for this caregiver population. The most obvious is the increasing prevalence of caregivers to the Alzheimer patient in the Canadian population. This invaluable resource to the health care system must be supported by nursing interventions directed at reducing the negative effects of caregiving. Research which enhances knowledge about the individual responses to caregiving will provide both a valuable foundation for further nursing research and guide the nurse's interventions appropriately.

Purpose of Investigation

The purpose of this investigation is: (a) to describe a sample of informal caregivers whose recipient of care is an institutionalized Alzheimer patient; and (b) to determine the relationships between meaning, psychological well-being and caregiver burden for this sample. This research will: (a) contribute to the developing body of nursing knowledge on caregiver burden and its relationship to meaning and psychological well-being; (b) increase the understanding of the caregiving experience for the nursing discipline, facilitating the development of appropriate and effective interventions for this population; (c) increase the health professional's sensitivity to the issue of caregiver burden; and (d) provide a foundation for further research in this area.

Research Questions

This investigation will address the following research questions:

1. What are the characteristics of a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

2. What is the meaning in life for a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

3. What is the psychological well-being of a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

4. What is the reported level of caregiver burden of a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

5. What are the relationships among selected caregiver characteristics, meaning, psychological well-being and caregiver burden for a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

CHAPTER II

Literature Review

The focus of this chapter is to present studies, research and contributions of others on the understanding of the meaning and psychological well-being to caregiver burden. Generally, caregiving research has used three research designs: descriptive, correlational, and causal-comparative.

Descriptive research depends heavily upon instrumentation for measurement and observation (Borg & Gall, 1989). This type of research produces statistical information about aspects of caregiving. Correlational research is a non-experimental method. It involves exploring the relationships between the variables using correlational statistics, which address the degree of relationship between any two variables. The strength, magnitude and direction of the relationship is studied and a large number of variables may be analyzed in a single study (Borg & Gall). The main disadvantage of this method concerns the degree of difficulty in establishing inferences from ex post facto research (Borg & Gall). The causal-comparative method explores causal relationships between variables using t-test and analysis of variance as the primary statistical procedures (Borg & Gall). This method enables the researcher to study cause and effect relationships

where experimental manipulation is not possible. Difficulty arises in establishing causality on the basis of the data, as it is collected ex post facto, after the causes have exerted their influence on the critical variable (Borg & Gall).

The literature review will address the following areas of study: (a) prevalence of Alzheimer disease; (b) characteristics of the caregiver such as gender, age, location, income, relationship of the caregiver to the recipient; (c) psychological well-being and its measurement; (d) caregiver burden and its measurement; and (e) meaning and its measurement.

Prevalence of Alzheimer Disease

Alzheimer disease is a chronic, progressive irreversible dementia characteristically seen in the elderly (Billig, 1988; Harding, 1990; Howard, 1990). In order to identify the significance of this problem in the Canadian society, the demographics of Canada will be addressed.

The demographics of Canada are changing, bringing with it major implications for the health care community. The considerable changes in the size, composition and distribution of the population have been attributed to three factors.

1. Current life expectancy has increased by about 25 years since 1900 (Simmons-Tropea & Osborn, 1987). Simmons-Tropea & Osborn (1987) defined life expectancy as the "average

number of years of life remaining at given ages according to the death rates prevailing at specified ages" (p. 404). Canadian male/female life expectancies differ. In 1987, male life expectancy was 73 years and female life expectancy was 80 years (Tregunna, 1990). The current life expectancy projections continue to demonstrate an increase. For example, in 1985-87, 65-year-old Canadian male and females could expect to live another 14.9 years and 19.1 years, respectively (Tregunna). These figures are slightly lower for the Newfoundland population, at 14.5 years for males and 19 years for females (Tregunna). The change in life expectancy also reflect changes in health status due to control of communicable diseases of infancy and childhood and general improvement in the living accommodations and quality of nutrition of the population.

2. The fertility rate has been declining since the early 1960's. In 1961, 42% of the Newfoundland population was aged 0-14 years. This figure has been diminishing consistently from 1961-1987 because of a negative growth rate of approximately 25% (Tregunna, 1990). This has yielded in a fewer number of children in the population. Consequently, the national demographics yield a proportionately larger older population (Stones & Fletcher, 1986).

3. A post World War II increase in the fertility rate has resulted in the baby boom. Beginning after the year 2020,

this group will become a numerically larger group of older persons (Simmons-Tropea & Osborn, 1987).

These factors have created an "aging population". This has major implications for a disease, like Alzheimer disease, which is characteristically seen in the elderly. Consequently, as the numbers of aged rise, it would be expected that the prevalence-incidence of this disease will increase. Therefore, since Alzheimer disease more likely occurs in the population aged 65+ and since that population is increasing in size, it would follow that both the incidence & prevalence of this disease in the total Canadian population will increase (Hill, 1988; Mann, 1985; Sneider & Emr, 1985). The prevalence of Alzheimer disease in the elderly Canadian population was estimated to be 55 per 1,000 in 1981 and is expected to rise to 74 per 1,000 in 2031 (Hill, 1988). The annual incidence rate is expected to increase from about one per 1,000 at age 60 to about one in 10 at age 95 (Hill, 1988). No Newfoundland statistics were available on the incidence/prevalence of Alzheimer disease.

There is another variable which influences these changes in prevalence/incidence of Alzheimer disease. It is the increased awareness of the public - in particular health care professionals - that Alzheimer disease is not a normal part of aging to be attributed to senility. This increased awareness has allowed Alzheimer disease a greater degree of social

acceptability in the public and a vitalized effort by health care professionals towards its diagnosis.

In summary, several factors have affected the changes in the incidence and prevalence of Alzheimer disease. These included: demographic changes which affected the size, distribution and composition of the Canadian population; a change in the public attitude towards the disease; and heightened awareness of both the disease and procedures for its diagnosis. It is estimated that 300,000 Canadians have Alzheimer disease and that this figure will increase to over 700,000 Canadians by the year 2020 (Alzheimer Society of Canada, 1989). This has major implications for society as the increased number of people afflicted with this disease will translate into an increased number of informal caregivers. Thus, research which increases the understanding of the informal caregiver population for nursing will enable the nurse to better achieve his/her goal - to provide the best possible care for the client.

Caregiver Characteristics

The family has been recognized as the caregivers for the care of the disabled and chronically ill (Bergman, Foster, Justice & Matthews, 1978; Cantor, 1983; Jones & Vetter, 1984; Rakowski & Clarke, 1985; Shanas, 1979). Research studies

consistently reported that one family member occupies the role as primary caregiver (Cantor, 1980; Cantor, 1983; Horowitz, 1985; Noelker & Poulshock, 1982). In addition, there was a preferential ordering in the selection of this individual; the hierarchy began with the spouse, if one was available, next the adult child and lastly a relative of the recipient of care (Chappell, 1991; Horowitz, 1985; Shanas, 1979). In three studies (Brody 1985; Cantor, 1983; Horowitz 1985), it was reported that the female spouse was the primary caregiver in two-thirds of caregiving dyads. Dyads referred to the caregiver and care-recipient couple. Daughters and daughters-in-law provided the bulk of care in the remaining caregiving dyads (Stone, Cafferata & Sangl, 1987), although sons did provide limited caregiving.

Many caregivers were aged themselves. According to Montgomery (1983), in the 1980s, 30% of caregivers were 74 years old and older, with the average age of a spousal caregiver being 65 years old. Day (1985), stated that "most adult children providing care to the very old are over 50 themselves" (p. 8) in Canada. Therefore, they may have their own health problems, which would complicate the caregiving role. As well, the caregiving population has been documented as generally having a low morale (Gilhooly, 1984) and a greater level of depression than the population norm (George 1984; Morris et al., 1989; Robinson, 1989).

Several caregiver characteristics will be addressed in this section, as they will contribute to the results and understanding of the caregiving experience. The following characteristics will be addressed: gender, age, living arrangement, income, relationship and the psychological well-being of the caregiver.

Gender

Research studies have consistently demonstrated a higher percentage of female caregivers than male caregivers. Shanas (1979) conducted a descriptive study, using a national U.S. survey of non-institutionalized elderly, and found a higher percentage of female caregivers (66%). Zarit, Reever & Bach Peterson (1980) conducted descriptive correlational study to identify the behaviours of the recipient and family visiting practices which were associated with higher levels of reported burden. The convenience sample of 29 American caregivers of Alzheimer recipients was used in the study and 86% of their sample was female. Other studies reported similar findings in their caregiver samples (Barusch & Spaid, 1989; George & Gwyther, 1986; Horowitz, 1985; O'Connor et al 1990). The proportionately larger number of female caregivers in the population was related to the demographics of the nation. Women live longer than men (Marshall, 1987), hence males often have a spouse available for the caregiving role. Also, the

hierarchical pattern of identifying the primary caregiver designated the daughter, then the daughters-in-law, as next in line after the spouse (Horowitz, 1985; Johnson & Catalano, 1981; Stoller, 1983; Tobin & Kulys, 1981).

Gender of the caregiver influenced the reported levels of burden. A causal-comparative study was conducted by O'Connor et al. (1990) in Britain, with 120 caregivers of demented care-recipients. The study compared the problems reported by the relatives (spousal, co-resident children, and non-resident children) and the strain that they experienced. The caregivers mean age was 82 years and a proportion were frail and physically disabled. The results indicated that wives caring for moderately demented husbands reported a significantly greater strain than male counterparts.

Similarly, Barusch and Spaid (1989) explored the gender differences in caregiving, using the correlational method, with an American sample of 131 caregivers. The caregivers were providing at least 20 hours of care per week for at least three months. The care recipients were not exclusively Alzheimer patients, although 51% of the care-recipients had this primary diagnosis. The Burden Inventory, which was developed by Zarit et al. (1980), was the unidimensional measure of burden, thus eliminating the exploration of gender differences within the dimensions of burden. The female caregivers, in this group, reported higher levels of burden

than male caregivers, after a stepwise linear regression model controlled other factors. Thirty-seven per cent of the variance in caregiver burden was explained by gender. Similar trends have been reported by other researchers (Fitting et al., 1986; Gilhooly, 1984; Pruchno & Resch, 1989; Young & Kahana, 1989). This difference may be accounted for by the following factors: (a) women had a greater tendency than men to report limitations and difficulties (Miller & Montgomery, 1990; O'Connor et al., 1990); (b) women were more emotionally involved in the caregiving role (Gilhooly, 1984; Horowitz, 1985); and (c) women were less willing than men to seek assistance with caregiving (Bergman et al., 1978; Chiverton & Caine, 1989). The literature therefore, acknowledged that reported levels of burden are affected by gender differences of the caregiver.

Age

The literature suggested that the age of the caregiver played a role in the reported level of burden. Barusch and Spaid (1989) explored the relationship between age differences and the reported level of burden. The sample consisted of 131 spousal American caregivers, who were providing at least 20 hours of care per week for at least three months. Fifty-one per cent of the care-recipient population were diagnosed with Alzheimer disease. The caregivers ranged in age from 55 - 89

years, spanning two generations. A significant negative correlation ($r = -.27$, $p < .01$) was reported between caregiver age and burden. Age accounted for 10% of the variance in burden. Therefore, the younger caregiver reported a higher level of burden.

Robinson (1983) conducted a correlational study to validate a screening instrument for caregiver strain. The recipients of care were recovering from acute hospitalizations for hip surgery and cardiac problems. The caregiver population was 85. The caregiver strain index demonstrated high internal reliability and was criterion referenced. The caregiver's age was negatively correlated with strain ($p = -.25$, $p < .05$). Although the sample was not generalizable to other populations, these results agreed with the research by Barusch and Spaid (1989).

George and Gwyther (1986) conducted a correlational study using a large heterogeneous sample of family caregivers (n=510) for patients with Alzheimer disease and related disorders. The sample contained caregivers of both the institutionalized and non-institutionalized care-recipient. Both care-recipient and caregiver characteristics were correlated with well-being. Well-being was defined as the opposite of burden with four generic categories of well-being (physical health, mental health, social participation, and financial resources). When the differences across caregiver

subgroups were tested, with effects of age statistically controlled, older caregivers reported a lower level of well-being.

A correlational study was conducted by Pruchno and Resch (1989) in Philadelphia, which studied 315 spousal caregivers of dementia patients in the community. The purpose of the study was to compare the mental health of husband and wife caregivers and to investigate the differences in predictors of burden and depression between the two groups. Burden was measured in two ways: (a) a global question (Overall, how burdened do you feel in caring for your spouse?) and (b) a modified version of previous instruments that had been used in the literature (Cantor, 1983; George & Gwyther, 1986; Zarit et al., 1980). The result was a 17-item scale with a co-efficient alpha of .89. Burden was inversely related to age for both burden measurements. Younger caregivers reported higher levels of burden.

The majority of these studies demonstrated a consistency in the caregiving literature with regards to the effect of age on caregiver burden. It has been postulated that this trend may be attributed to role theory (Brody, 1981; Pruchno & Resch, 1989; Scharlach, 1987; Young & Kahana, 1989). A younger caregiver often has a greater number of roles to fulfil and caregiving may cause "role overload".

Living Arrangement

Limited caregiving literature has addressed the living arrangements between the caregivers and their recipients. The results indicated that co-resident caregivers reported a greater level of burden, but burden was evident in all caregivers, regardless of accommodation. The majority of the studies reviewed reported living arrangements of adult children caregivers. There was a paucity of literature which addressed the caregiver, living independently of the institutionalized care-recipient.

Pett et al. (1988) conducted a causal-comparative study which compared the experience of caregiving for co-resident caregivers and those who were caregivers of either institutionalized care-recipients or care-recipients who lived in a separate residence. All the care-recipients were diagnosed as having dementia. The sample of 181 caregivers was accessed through support groups from New York to California. There were 56 co-resident caregivers, 63 caregivers with care-recipients residing separately in the community and 59 caregivers of institutionalized care-recipients. The Zarit Burden Inventory, a 22-item index which was both reliable and valid (Zarit & Zarit, 1982) was used to assess burden. The range of scores on this scale was from zero (low) to 88 (high). The results indicated that co-resident caregivers reported the highest level of burden (mean score of 47.2). The next highest level

of burden was reported by caregivers of institutionalized care-recipients (mean score of 42.8). The lowest level of burden was reported by caregivers of care-recipients who resided elsewhere in the community (mean score of 34.8). The levels of burden for each of the categories was significant at the .001 level. The study supported the conviction that caregiver burden may be less for caregivers of the institutionalized care-recipient, but it was still quite evident.

O'Connor et al. (1990) conducted a causal-comparative study which examined: (a) the frequency and severity of problems associated with dementia; (b) the relationship between the problems reported by relatives; and (c) the level of strain that was experienced. The study was conducted in Britain with a sample consisting of 120 caregivers. The caregivers were grouped as follows: (a) spousal caregivers, who were co-residents with the care-recipient, (b) adult child caregivers, who lived independently from institutionalized care-recipients, and (c) adult child caregivers, who co-resided with the care-recipients. The results indicated that co-resident children reported a greater strain than either of their counterparts who lived independently from the care-recipient. As well, they reported a greater strain than spousal caregivers. Wives also reported a greater strain than husbands. Strain was evident across all groups, regardless of

accommodation. This study upheld the results of Pett et al. (1988).

Staight and Harvey (1990) conducted a causal-comparative study between caregivers of mentally impaired co-resident husbands and caregivers of institutionalized spousal care-recipients. The non-random sample consisted of 50 women from OR who were accessed through public and private health service agencies, and directors and social workers of nursing and foster homes. No significant differences in mean scores were found between the two groups for the following factors: loneliness, depression, perceived health status, financial status and life satisfaction.

The findings of these studies demonstrate that burdens from caregiving exist, regardless of living arrangements. Other researchers, using a sample of caregivers to both institutionalized and non-institutionalized recipients, have found similar results (Coppel, Burton, Becker & Fiore, 1985; George & Gwyther, 1986; Snyder & Keefe, 1985; Stoller & Pugliesi, 1989; Zarit et al., 1980).

Income

Limited research was found concerning financial resources of caregivers. The studies that were reviewed lend support to the idea that there was no significant difference between the financial status of the caregiver of the institutionalized

care-recipient and the caregiver of the coresident care-recipient.

Fengler and Goodrich (1979) first mentioned income as an issue for caregivers. The study examined the special needs and problems of elderly wives caring for chronically ill or disabled husbands in a northern New England city. The sample consisted of 34 men (care-recipients) and women (caregivers) who were interviewed, observed, and had case materials reviewed. The men in the sample were randomly assigned to either a workshop or control group and were followed for a six month period. Life Satisfaction Scale was administered to the wives and the scores were ranked as high life satisfaction (HLS) and low life satisfaction (LLS). These two groups were compared in order to establish the cause of the difference. The results indicated that the LLS group did, in general, report their income as inadequate, whereas, the HLS group generally reported their income as adequate. It was important to note that this study did not address the concept of burden, but did identify income as an issue for the life satisfaction of the caregiver.

Cantor (1983) conducted a causal-comparative study to explore the caregiving experience in the United States and its affects on the lives of caregivers of the frail elderly. The data was drawn from a larger study (n=111), which was funded by New York City to address the "Impact of the Entry of

Formal Organization on the Informal Support System of Older Americans" (p. 597). The caregivers were categorized by their relation to the care-recipient: spousal, child, and relatives/friends/neighbours. One-way analysis of variance indicated significant financial strain in all three categories of caregivers. The results further indicated that spousal caregivers had the lowest income level, according to the Hollingshead Two Factor Index of Social Class (Hollingshead, 1958). The child caregivers reported that they barely managed on their incomes due to family and caregiving financial responsibilities. It should be noted that some of the caregivers lived with the recipients and some did not, yet they all felt varying degrees of financial duress due to the caregiving role.

Haley, Levine, Brown & Bartolucci (1987) conducted a comparative study, in Alabama, with co-resident caregivers of Alzheimer patients. The non-random sample of caregivers had a mean age of 57.8 years and they were matched with a control group with a mean age of 53.4 years. The sample size was 44. The demographic and descriptive data revealed significant differences in family income between the control group and caregiver group ($p < .05$). The analysis of these results indicated that many of the caregivers were women who had quit their jobs because of caregiving responsibilities, hence their income was significantly lower.

Pett et al. (1988) conducted a causal-comparative study which compared the experience of caring for a recipient with dementia of co-resident caregivers with those who were caregivers of either institutionalized care-recipients or care-recipients in a separate residence. The sample of 181 caregivers was accessed through support groups from New York to California. There were 56 co-resident caregivers, 63 caregivers with care-recipients residing separately in the community, and 59 caregivers of institutionalized care-recipients. Data regarding the caregiver's income was obtained in the caregiver profile section of this study and significant differences were found between the groups. Co-resident caregivers reported significantly lower incomes than the other two groups and fewer of these caregivers were employed outside the home. This supported the results by Haley, Levine, Brown & Bartolucci (1987).

Staight and Harvey (1990) conducted a causal-comparative study to compare elderly female caregivers who resided with their impaired spouse and elderly female caregivers of an institutionalized impaired spouse. The non-random sample was composed of 50 women (25 in each group) in the state of Oregon, USA. The 1986 household income from all sources was reported by the subjects and difference in financial status was addressed. Although the sample size was relatively small,

no significant difference was found between the mean incomes of the two groups.

These studies addressed a financial strain that was reported to be due to the responsibilities of caregiving. One study reported that there were no significant differences between the income levels of co-resident caregivers and caregivers of the institutionalized. No studies were found which addressed this aspect of caregiving longitudinally, therefore it cannot be concluded that the financial duress was entirely due to caregiving responsibilities. It may be suggested that privatization versus subsidization of health care systems may play a role in the reported level of financial burden. Additional research is needed in this area.

Relationship of the Caregiver to the Care-Recipient

The caregiving research reported that the relationship of the caregiver to the care-recipient had an effect on caregiver burden. The fact that the majority of caregivers were spouses, followed by children, and others (friends/neighbours/relatives) was consistently substantiated in the literature (Cantor, 1983; Chappell, 1991; George & Gwyther, 1986; Horowitz, 1985; Shanas, 1979; Snyder & Keefe, 1985; Stone et al., 1987; Young & Kahana, 1989). Cantor (1983) conducted a causal-comparative study to explore the caregiving experience in the United States and how it affected the lives

of caregivers of the frail elderly. The data was drawn from a larger study (n=111), which was funded by New York City to address the "Impact of the Entry of Formal Organization on the Informal Support System of Older Americans" (p. 597). The caregivers were categorized by their relation to the care-recipient: spouse, child, and relatives/ friends/neighbours. The results indicated that spousal caregivers reported the highest level of physical and financial strain, child caregivers reported less physical and financial strain, and relatives/friends/neighbours reported very little strain of either type. Emotional strain was evident across all categories of caregiver, except neighbours and friends. The impact of caregiving was most severe for spousal caregivers, then children, and less severe for relatives. The friends/neighbours were the least severely affected. All spousal caregivers were co-residents with the care-recipient, but this was not the case with the other categories of caregivers.

George and Gwyther (1986) conducted a correlational study using a large heterogeneous sample of family caregivers (n=510) for patients with Alzheimer disease and related disorders. The sample contained caregivers of both the institutionalized and non-institutionalized care-recipient. Both care-recipient and caregiver characteristics were correlated with well-being. Well-being was defined as the

opposite of burden with four generic categories: physical health; mental health; social participation; and financial resources. The caregivers were divided into three categories: spousal; adult children; and other relatives. Statistically controlling for age, the results indicated that spousal caregivers were the most vulnerable to the effects of caregiving, among the three groups. The spousal caregivers reported: lower levels of well-being; more doctor's visits; poorer self-rated health; and lower incomes. The child caregiver was the next most vulnerable, reporting slightly lower levels of well-being than the spousal caregivers, lowered affect balance, and a stronger inclination to use psychotropic drugs. The relatives were the least affected by the caregiving role. This supported the results of the study by Cantor (1983).

Young and Kahana (1989) studied the strains that caregivers, in a metropolitan area in the United States, experienced while caring for older heart patients, who had a confirmed heart attack. Data was collected six weeks and one year after discharge in a sample of 183 patient-caregiver dyads. The caregivers were subdivided into spousal and child, in order to compare the effects of caregiving between the two groups. The results indicated that, although both groups provided similar amounts of total care to the care-recipients, the child caregivers reported higher levels of burden, using

the Zarit Burden Inventory (Zarit et al., 1980), and greater levels of role conflict, using a scale that was created for this study. The health and condition of the recipient, prior to this hospitalization was not addressed, therefore, these results may be attributed to the acute nature of the recipient's condition, as opposed to the progressive nature of caregiving for the elderly.

Miller, McFall and Montgomery (1991) conducted a path analysis to test the validity of a model, which the authors proposed. The model contained two constructs which warranted definition. They were 'personal burden' and 'interpersonal burden'. Personal burden "represented the confinement associated with limitations in personal actions and activities as a result of providing care" (p. S13) and interpersonal burden "represented interpersonal tensions that underlaid the caregiver's appraisal of selected difficulties that disturbed established relationship patterns" (p. S13). The sample, which was drawn from the 1982 National Long Term Care Survey in the USA, consisted of 940 spousal and adult child caregivers. The results indicated that spousal caregivers reported more personal burden, higher stress levels, and greater caregiver involvement than adult child caregivers, but adult child caregivers reported higher levels of interpersonal burden.

The results from the studies were mixed, yet demonstrated both spousal and child caregivers were affected by the

caregiving experience. More research is necessary in this area.

Psychological Well-Being of the Caregiver

The psychological well-being has been defined in the literature as the "presence of positive emotions such as happiness, contentment, joy, peace of mind and the absence of negative emotions such as fear, anxiety, and depression" (Reker & Wong, 1984, p. 24) that is experienced by the caregiver. No studies were found which addressed both the negative and positive components of the construct in the caregiving population. There was literature which addressed negative affect and it suggested a greater prevalence of depression within the caregiving population. A descriptive article by Lezak (1978) examined the special problems of living with a brain-injured individual. The data was collected from the clinical assessments of 200 family members of brain-injured patients at Veterans Administrative Hospital in OR. The prevalence of depression within the population was heralded as being a major problem. Most family members suffered from depression. For some, it was a chronic influence in their lives and others an episodic experience. "Among these families, depression is as natural and expected as is mourning among the bereaved" (p. 595).

Haley, Levine, Brown & Bartolucci (1987) conducted a quasi-experimental study in the United States to assess the specific effects of caregiving on psychological, social, and health functioning of the caregiver for a relative with dementia. The sample consisted of a group of 44 caregivers and a matched control group. The Beck Depression Inventory (BDI), a reliable-valid tool, was administered to both groups. It was reported that the caregiver group was significantly more depressed than the control group ($t = 4.07$, $p < .001$).

Kiecolt-Glaser et al. (1987) found similar results in a quasi-experimental study of caregivers of Alzheimer patients in the state of Ohio, USA. This study, which investigated the possible health-related consequences of long-term stress of caregiving, used a caregiver group and a matched control group (n=34). The Becker Depression Inventory was administered to both groups and it was reported that the caregiver group had significantly higher scores on this instrument, indicating a higher level of depression in the caregiver group.

Kinney and Stephens (1989b) conducted a descriptive correlational study in the USA which compared the level of depression between a stratified random community sample of younger individuals and a convenience sample of caregivers of patients with Alzheimer disease (n=60). The caregiver population were reported to be significantly more depressed ($p <$

.001) than the comparison sample using the Symptom Check List 90-Revised (Derogatis, 1983). It should be noted that an older age in the caregiver sample may have influenced the results.

Gallagher, Rose, Rivera, Lovett and Thompson (1989) conducted a causal-comparative study to explore the extent of clinical depression in several sub-groups of family caregivers (n=158) to dementia patients in California, USA. The Beck Depression Inventory was used to measure depression. The results indicated that depression was more prevalent in the caregiver population than the population norm and the extent of depression was not related to care-recipient's level of impairment. The caregivers were divided into volunteers and help seekers. Help seekers, who had spent statistically significant longer length of caregiving, were found to be more depressed.

The above studies suggested that depression was more common to caregivers, as a population, than non-caregivers.

Measurement of the Psychological Well-Being of the Caregiver

Scales which measured the psychological well-being of an individual abound in the literature, yet no scale was found which had been developed specifically for the caregiving population. Two scales will be presented: (a) Beck Depression Inventory (BDI) which abounds in the caregiving litera-

ture, measuring the sphere of negative affect in psychological well-being; and (b) Memorial University of Newfoundland Scale of Happiness (MUNSH) which has the ability to measure both the negative and positive affect components of psychological well-being. According to Kozma and Stones (1980), the construct of happiness, which is measured by the MUNSH, may be most representative of mental health constructs used by gerontologists.

The Beck Depression Inventory was developed by Beck, Ward and Mendelson (1961) in order to measure behavioral manifestations of depression with a general psychiatric out-patient population. It has been used extensively in the caregiving literature (Fiore, Becker & Coppel, 1983; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Haley, Levine, Brown & Bartolucci, 1987; Schulz, Visintainer & Williamson, 1990; Staight & Harvey, 1990). The items reflected the medical criteria for depression. Its developers reported split-half reliability of 0.86. Face validity was reported by Kane and Kane (1984). Some of the items in this tool were very wordy which could be confusing to the elderly population, for example, "I am not particularly pessimistic or discouraged about the future" or "I feel that I have accomplished very little that is worthwhile or that means anything". This scale has not been used in studies of the Newfoundland population.

The Memorial University of Newfoundland Scale of Happiness (MUNSH) was developed by Kozma and Stones (1980) and measured the psychological well-being of a population through the construct of happiness. It consisted of 24-items, which included 5-items of positive well-being, 5-items of negative well-being, 7-items of general positive experience, and 7-items of negative experience. The wording of the items was easily understandable and the dichotomous scoring further simplified its administration.

The psychometric properties of the MUNSH were initially tested in the elderly Newfoundland population (n=301) from diverse settings (urban, rural, and institutionalized) (Kozma & Stones, 1980). The results of this study indicated that the MUNSH was a significantly better predictor of 'happiness at the moment in time' than three other scales of happiness (Affect Balance Scale, Life Satisfaction Index-Z, Philadelphia Geriatric Center Scale). Cronbach's alpha, which was the measure of internal consistency, was calculated to be .85. The test-retest reliability was reported to be .70.

This tool was revalidated in a study in London, Ontario with a sample of 51 institutionalized elderly women (Kozma & Stones, 1983). The criterion validity correlations were reported to be .75-.86. This study indicated that the tool was also valid in the Ontario population, which expanded its use to larger urban centers.

A comparative study was conducted in London, Ontario by Kozma, Stones and Kazarian (1985) to examine if the MUNSH retained its psychometric properties with a younger sample and to examine its use as a tool to discriminate between community and clinical samples. The sample consisted of 40 subjects from the community and 117 subjects who had been recently admitted to the London Psychiatric Hospital. The sample was divided into two categories by age, those under 30 and those over 30. The results indicated a reliability co-efficient of .86 and effective discrimination between the community and clinical groups for both age groups. This study extended the psychometric properties of the MUNSH to a wider age range.

Both these tools measure psychological well-being of a sample. The BDI was more restrictive, measuring only the presence or absence of depression, and has not been used in the Newfoundland population. The MUNSH allows more flexibility, utilizing the broader construct of happiness and has been used in the Newfoundland population.

Caregiver Burden

The literature review will address five dimensions of caregiver burden as defined by Novak and Guest (1989). They are: time dependence burden, developmental burden, physical burden, emotional burden and social burden. Physical and

emotional burden will be grouped together in accordance with the literature, which addressed both these dimensions of burden in a single study (Brody, 1985; Cantor, 1983; Pruchno, Kleban, Micheals & Dempsey, 1990; Schulz et al., 1990; Snyder & Keefe, 1985).

Time Dependence Burden

This dimension of burden described the restrictions placed on the caregiver's time due to the caregiving role. The literature referred to the all-consuming nature of caregiving (Mace & Rabins, 1981; Noelker & Poulshock, 1982), but Novak and Guest (1989) were the first researchers to attribute a dimension of burden to this facet. Horowitz (1985), in a review of the literature for caregiving to the frail elderly, referred to the variation in time restrictions of caregivers. "Caregiving can range from occasional errands to round-the-clock care" (p. 202) involving an average of three weekly hours to well over 40.

A descriptive study was conducted by Sanford (1975) in London, England to identify the types of problems encountered by the caregiver when caring for mentally-impaired elderly at home and to measure the tolerance of caregivers to these problems. Fifty caregivers were interviewed and a standard form, which was not identified, was used to collect the frequency of problems. Qualitative data was also collected to

substantiate the results. It was reported that the caregiver's lack of time for themselves was the most difficult to tolerate.

Zarit et al., (1980) conducted a descriptive correlational study of 29 caregivers of dementia to identify the behaviours of the recipient and family visiting practices which were associated with a high level of burden. The Burden Interview, which resulted in a unidimensional score for overall burden, acknowledged the time factor specifically in item 3 "... I don't have enough time for myself" (p. 651).

The Cost of Care Index was a 20-item tool created to be a component of a comprehensive assessment for the identification of problem areas for family caregivers of the impaired elderly. Based upon previous work by Zarit et al. (1980) and Lau and Kosberg (1979), it was developed by Kosberg and Cairl (1986). It was composed of five subscales which were: physical, emotional, value, care-recipient as provocateur and economic costs. High internal consistency was reported by its authors. The dimension of time dependence burden was referred to in an item of the instrument "I feel that caring for my elderly relative disrupts [will disrupt] my routine in my home" (p. 276).

Another scale, The Caregiving Hassles Scale was developed in the United States by Kinney and Stephens (1989a) for the evaluation of daily hassles for caregivers of Alzheimer

disease. The pilot study resulted in a scale that was comprised of 42-items in five subscales and was reported to be psychometrically sound by the authors. The dimension of time dependence burden was inherent in six items in the instrumental activities of daily living subscale (i.e. day supervision, night supervision, transport), as well as in all the items in the basic activities of daily living subscale.

Miller and Montgomery (1990) conducted a national study in the USA with 1167 family caregivers of the frail elderly. The purpose of the causal-comparative study was to identify the factor which most limited social activities for caregivers. The subjective appraisal of care demands was measured by appraising the caregiver's time pressure, relationship difficulties and global stress. The index of time pressures summed the responses to two dichotomous questions which were: (a) I have to give him/her almost constant attention, and (b) I have to take care of him/her when I don't feel well enough. Time pressure was a significant factor in all the categories of caregiver (spouse, adult-child, intergenerational household or living apart).

Staight and Harvey (1990) conducted a causal-comparative study in OR to compare elderly women caregivers who resided with their impaired spouse and elderly women caregivers of an institutionalized impaired spouse. The non-random sample was composed of 50 women (25 in each category). The time con-

straints between these two groups was found to be significantly different. The caregivers of institutionalized spouses reported that they had more time for themselves than the co-resident caregivers.

These studies demonstrated the existence of a time dependence burden dimension for caregivers. This concept has been developed by Novak and Guest (1989) in the Caregiver Burden Inventory to refer to the time commitment in caregiving.

Developmental Burden

According to Novak and Guest (1989), pioneers in the recognition of the developmental burden, the caregiving role was incongruent with the caregiver's expectations for his/her life at that age/stage of development. It was based on stage theories which assume that everybody goes through life in the same way (universality) and everybody goes through the stages in the same order (sequentiality) (Troll, 1982, p. 15). Neugarten and Hagestad (1976), cited in Novak and Guest (1989), conclude from their research that "... the age norm system ... also created an ordered predictable life course, it created timetables, it set boundaries for acceptable behaviour at successive life stages" (p. 45).

Brody (1981), in a lecture, which was presented to the 37th Annual Scientific Meeting of the Gerontological Society

of America in San Antonio, Texas, argued that parent care may be a normative experience in life, but it is not a developmental stage. It was not an experience which fits a time slot in the orderly stages of life. The variations in both caregivers and caregiving situations do not lend credence to universality in the experience, hence the caregivers "do not share a single developmental stage in life" (p. 23). Consequently, the caregiving experience could place the caregiver "off-time" in his/her development, causing burden.

Fengler and Goodrich (1979) published a study which examined the special needs and problems of elderly wives caring for disabled or chronically ill husbands. The data was collected with multiple interviews, on-site observations and case materials in a convenience sample of 34 care-recipient men and their spousal caregivers in a northern New England city. The men in the sample were randomly assigned to either a workshop or control group and were followed for a six month period. The sample results of the life satisfaction scales A & B (Neugarten, Havighurst & Tobin, 1961) was compared with the results from a national study by Harris (1975). It was reported that the sample median score was significantly lower than the national median score, even though the national sample had included low income and very old elderly. The developmental burden of care was referenced in the qualitative interview data. "I cry a lot because I never thought it would

be this way". "No one expects this in a family." "I didn't expect this." (p. 178).

No further studies were found which specifically referred to the developmental dimension of burden.

Physical and Emotional Burden

These two burdens will be addressed together in accordance with much of the caregiving literature. These burdens referred to changes in the caregiver's physical and emotional health due to the caregiving experience and were widely recognized in the caregiving literature (George & Gwyther, 1986; Horowitz, 1985; Kinney & Stephens, 1989; Robinson, 1983; Zarit et al., 1980).

Cantor (1983) conducted a causal-comparative study to explore the caregiving experience in the United States and how it affected the lives of caregivers of the frail elderly. The data was drawn from a larger study (n=111) which was funded by New York City to address the "Impact of the Entry of Formal Organization on the Informal Support System of Older Americans" (p. 597). The caregivers ages ranged from 20 - 75 years with approximately 60% being 60+ years. It was reported that 84% of the caregivers perceived their own health as fair or poor. Also on a 3-point measure, was strain that was experienced in the areas of emotional, physical and financial. One-way analysis of variance was used to statistically analyze the

data. A significant main effect was reported for all caregivers, therefore all caregivers experienced some degree of strain due to the caregiving role. The caregivers ranked the strains as emotional first, physical second, and financial last.

In 1985, Snyder and Keefe conducted a descriptive correlational study which addressed two things: (a) the extent that a caregiver's informal support network was actually providing support; and (b) the health problems associated with caregiving. The study reported the findings from caregiver questionnaire data which was part of a Task Force on Caregivers that had been organized by the Older Women's League in Washington, DC. The sample consisted of 117 caregivers (whose age is not specified) of a disabled population: 45% of this sample suffered from dementia. The method of collection was self-report on a 21-item questionnaire designed to elicit information about caregiving in order to enhance understanding about the subject. The results stated that 70% of the caregivers reported a decline in physical health because of the caregiving role. The health problems fell into two broad categories: (a) physical, which included both physical and emotional problems such as stress, depression, physical exhaustion, cardiac and back problems, stomach ailments, weight changes, and sleeplessness; and (b) negative lifestyle changes which were described as a loss of interest

in all activities, "cabin fever", loss of time for oneself, and/or loss of friends.

Stone, Cafferata and Sangl (1987) conducted a descriptive study which drew data from an American National Long-Term Care Survey for 6393 caregivers. The caregivers were operationalized as those who were 14 years and older and providing care for a recipient who was impaired in one or more activities of daily living. The sample was divided into three subcategories: (a) spouses; (b) children; and (c) others (friends/relatives/neighbours). The self-report health indicator asked the caregivers to rate their perceived health as excellent, good, fair or poor. One-third of the caregivers perceived themselves to be less healthy than their same-aged peers: physical and emotional health were not separated. The results showed that almost one-half of the spousal caregivers and one-third of the adult child caregivers considered their health to be poor.

Haley, Levine, Brown & Bartolucci (1987) conducted a comparative study, in Alabama, with caregivers of Alzheimer patients. The non-random sample of caregivers had a mean age of 57.8 years and they were matched with a control group with a mean age of 53.4 years. The sample size was 44. Significant differences were noted between the control group and caregiver group. The caregivers had: (a) more depression than controls, according to the Beck Depression Inventory; (b) a poorer health status than controls; and (c) a higher

utilization of health care, greater number of physician visits and higher utilization of prescription medications.

It is important to note that there were no longitudinal studies which documented the caregiver's health prior to caregiving and compared the health status at various points in the caregiving experience. These studies were one-point-in-time and it was possible that the elderly caregiver may have experienced a decline in health with advancing age. Yet, the study by Haley, Levine, Brown & Bartolucci (1987) which used a stronger research design, demonstrated that a decline in both physical and mental health was due to the caregiving experience.

Social Burden

Social burden was defined in the context of roles and the caregiver's feelings of role conflict. Role theory referred to a particular perspective of human behaviour and a special language, used in the context of a method of communicating, as opposed to a speech or dialect. "Individuals in society occupied positions and their role performance in these positions was determined by social norms, demands and rules" (Thomas & Biddle, 1966 p. 4). Roles referred to the "social script". Role conflict occurred when an individual was confronted with incompatible expectations and conflicting sets of role expectations. An internal conflict occurred where the

individual must sacrifice some, at least, of both or more sets of expectations or choose one alternative and sacrifice the other (Thomas & Biddle, 1966).

Fengler and Goodrich (1979) conducted a study which examined the special needs and problems of wives of elderly disabled and chronically ill men. They referred to the wives as "the hidden patient". The data was collected in a New England city for a convenience sample of 34 caregivers by multiple interviews, on-site observation, and case materials. The men (care-recipients) in the sample were randomly assigned to either a workshop or control group and were followed for a six month period. The qualitative data referred to both the multiplicity of roles inherent with the caregiving role and role conflict. One caregiver, to a husband with advanced multiple sclerosis which required a lot of care, also cared for a grieving mother. "Mother's expectations of me are getting unreasonable. I can't continue to cart her around because I can't leave my husband alone." (p. 179).

Brody (1981), in a discussion paper for a symposium which was sponsored by the Gerontological Society of America in San Diego on the family, coined the phrase "women in the middle". She referred to 'middle' from a generational standpoint and discussed the demands of various roles competing for time and energy of the caregiver. Brody referred to the possible roles of: paid worker, caregiving daughters and

daughters-in-law, wives, homemakers, mothers and grandmothers. Conceptualization of role conflict was certainly easily seen with so many roles needing attention.

Similarly, Cantor (1983) conducted a causal-comparative study which explored the effects of the caregiving experience on 111 caregivers of the frail elderly. The data was drawn from a larger study in New York which explored the "Impact of the Entry of the Formal Organization on the Informal Support System of Older Americans". The results indicated that strain was evident for all caregivers, but that it was experienced differently for different groups of caregivers: spouse, child, relative/friend/neighbour. It was noted that the adult child caregiver suffered from a multiplicity of roles.

Stoller and Pugliesi (1989) conducted a study to test the relationships in a model, which the authors created, of caregiver burden and well-being with a sample of 461 caregivers in New York region. Two interviews were carried out. Burden was assessed using a 13-item summated rating based on four previously validated measures of burden. The caregiver's multiplicity of roles was a variable in the model. Multiple regression analysis was used to test the model. Results suggested that competing family responsibilities such as child-rearing and financial responsibility, in combination with increased time need for caregiving, contributed to burden.

Young and Kahana (1989) studied the strains that caregivers, in a metropolitan area in the United States, experienced while caring for older heart patients. Data was collected six weeks and one year after discharge in a sample of 183 patient-caregiver dyads. Role conflict was measured using the Role Conflict Scale which had alpha reliability of .87. Multivariate analysis of variance was the statistical analysis which demonstrated the main effect of role conflict to be significant ($F = 4.69$, $p < .05$). Role strain was not exhibited uniformly amongst the caregivers, but varied with gender and relationship to patient. Daughters reported greater role conflict. This would support Brody's "woman in the middle".

The results of these studies suggest that a multiplicity of roles may contribute to the level of burden that is experienced by the caregiver.

Measurement of Caregiver Burden

The measurement of such a complex concept of caregiver burden for caregivers of individuals with dementia was a formidable task. The first tool of this kind was developed by Zarit et al. (1980). The scale consisted of 29 items which reflected the multidimensional nature of burden, yet its scoring was summative which precluded a separate evaluation of each dimension. The items were derived from a comprehensive

review of the gerontological literature, clinical experience with caregivers and scored on a likert-type scale from "not at all" to "extremely" relevant.

Building upon the work of Zarit et al. (1980), George and Gwyther (1986) developed a tool to measure Caregiver Well-being. "Caregiver burden and caregiver well-being are but opposites of the same coin" (p. 253). This tool consisted of items representing four dimensions of well-being: physical, mental, social and financial. Reliability of the subscales ranged from .79 - .95.

Kinney and Stephens (1989a) developed a tool which conceptualized hassles of daily living. It was based on stress theory. The Caregiving Hassles Scale was comprised of 42 items derived from the caregiving literature and from discussions with caregivers. The subjects were asked to indicate which events had occurred during the past week and the degree to which they were appraised as a hassle (4-point scale from "not at all a hassle" to "a great deal of hassle"). The developers reported that test-retest reliability and internal consistency were conducted, but did not relate any results.

Novak and Guest (1989) extended the work of the previous researchers and developed the Caregiver Burden Inventory (CBI). This multi-dimensional burden measurement had five distinct subscales. The five subscales were identified by

factor analysis and they accounted for 66% of the variance. Dimension-specific patterns of caregiving impact can be profiled using this tool. The five dimensions were: time dependence, developmental, physical, social and emotional burdens. The items were devised by the developers in a Canadian study using a sample of 107 caregivers of confused or disoriented older people - 28 men and 79 women. Half of the caregivers cared for their relative in the community and the other half cared for a person who had been institutionalized. Each of the caregivers was interviewed in their homes using a questionnaire with both open-ended and fixed choice questions. The questions were derived from previous burden literature (Poulshock & Deimling, 1984; Robinson, 1983; Zarit et al., 1980). A factor analysis was conducted and all factors were found to be of approximately equal value. Internal consistency of the factors varied from .77-.86. This tool was a practical and applicable instrument for measuring caregiver burden.

Vitaliano, Russo, Young, Becker and Maiuro (1991) developed a tool to screen caregiver burden of, specifically, spousal caregivers. This tool viewed burden in two dimensions, subjective burden and objective burden, and had a subscale for each. It was composed of 25 items. The psychometric properties of this measure reported: test-retest reliability of .70, good internal consistency and validity (content, divergent, convergent and criterion). This tool did not claim to

measure the full domain of caregiving, rather those caregiving experiences that were potentially related to stress.

In summary, the comparison of studies involving caregiver burden was problematic. These problems have arisen from variations in conceptualization and lack of standardized measuring instruments and convenience sampling (Cantor, 1983; Robinson, 1983; Zarit et al., 1980). Recipients of care (frail elderly, cognitively impaired, disabled) and their circumstances were varied and could be reflected in the measures of burden with the caregiver populations. The use of a multidimensional perspective was recommended by Poulshock and Deimling (1984) and the necessity of conceptual clarification was recognized by Stephens and Kinney (1989). Variations in theoretical frameworks and measurement criteria were reflected in the titles of the research studies. For example: (a) caregiver strain (Cantor, 1983; Sheehan & Nuttall, 1988); (b) physical and emotional manifestations of caregiving (Pruchno, Kleban, Michaels & Dempsey, 1990; Schultz et al., 1990); and (c) consequences of caregiving (Wilson, 1990). The dominant theories in the caregiving literature have been stress and coping theory (Lazarus & Folkman, 1984) and role theory (Brody, 1985; George & Gwyther, 1986).

These studies have investigated at least one of the dimensions of caregiver burden as defined by Novak and Guest (1989). Comparison of the research of a multifaceted con-

struct like caregiver burden was difficult, but the body of knowledge in this area was developing and common trends were becoming apparent. For example, there was a general consensus that the caregiving role had consequences for the caregiving population and that this population was seen as vulnerable.

Meaning

Meaning was defined as those attitudes, values, beliefs and principles that people use to organize their behaviour and to interpret their experience (Hansen, 1979). Very limited research has been done regarding the effects of meaning and caregiver burden. Yet, the caregiving literature has acknowledged individual and varied responses to this experience. Brody (1985), in the discussion paper on Parent's Care as a Normative Family Stress for the 37th Annual Scientific Meeting of the Gerontological Society of America in San Antonio, Texas, acknowledged that individuals experience the caregiving experience differently. The reported objective measures of the number of tasks or hours of caregiving performed with similarly impaired recipients of care appear to be the same, yet the reported level of burden varied.

Fittings et al. (1986) conducted a causal-comparative study in Baltimore, MD, for 28 husband and 26 wife caregivers of demented patients (n=54). It was reported that female

caregivers reported higher levels of burden than male caregivers. One of the explanations offered by the researchers for the variation in results was the different way in which men and women viewed the caregiving role.

Zarit, Todd and Zarit (1986) conducted a descriptive correlational study of 64 spousal caregivers of dementia patients (institutionalized and non-institutionalized) in the USA in order to identify changes in the caregiving experience over a two year period. The caregiving tasks and the severity of impairment of the recipient did not account for the degree of burden experienced by the caregiver. The impact of caregiving remained varied. The authors advised that an important issue in research on caregivers was the variability of the burden reported - how the caregivers differed in their response to caregiving demands from one another.

Hasselkus (1988) conducted a series of four ethnographic interviews with fifteen family caregivers of the frail elderly in the community. The purpose of the study was to elicit data on the meaning of caregiving in order to increase an understanding of this experience for the formal health care provider. Five themes of meaning dwelt within the descriptions of the data. They were: sense of self, sense of managing, sense of future, sense of fear or risk, sense of change in role and responsibility. The beliefs of the caregiver directly affected the interpretation of the caregiving experience and

were demonstrated through attitudes and behaviours. According to the author, the formal health care provider often misinterpreted these themes and unnecessary stress was inflicted upon all of the parties involved. An increased understanding of the effects of meaning was indicated.

Sheehan and Nuttall (1988) stated that "the meaning that family caregivers attached to the caregiving experience was more closely associated with the consequences of caregiving than the actual tasks and numbers of hours involved" (p. 92) This hypothesis was explored in a correlational study in CT, USA, which involved 98 family caregivers who responded to a self-administered questionnaire. The purpose of the study was to examine contributions of conflict, affection, caregiver satisfaction, distress, as well as, the objective demands of caregiving in predicting caregiver strain and negative emotion. The statistical analysis of multiple stepwise regression was used. It was concluded that subjective factors, such as affection, conflict and satisfaction, played an important role in explaining the negative consequences of caregiving, such as increased strain.

Motenko (1989) conducted interviews in MA with 50 female spousal caregivers to demented husbands who were living at home. The study hypothesized that caregivers who reported greater gratification from the caregiving role would also report higher levels of well-being and the levels of frustra-

tion in the caregiving role would be related to greater reported distress. The measures used in the study were: (a) the Dupuy Psychological General Well-Being Index, which consisted of 22 items of high internal consistency reliability (.94) and a test-retest reliability from five studies ranging from .50-.86; (b) a Frustration scale which was adapted from the Emotional Response to Stigmatization Scale and had an acceptable alpha co-efficient of .57; and (c) global questions pertaining to gratifications which were substantiated in the literature. The caregiver's meaning of the experience was addressed by asking the wives to choose the most important reason for taking care of their husbands. The list of reasons that was used had been derived from caregiving literature. The results reported that wives who selected reciprocity and nurturing as their meaning were highly gratified and attained high levels of well-being.

Pruchno and Resch (1989) conducted a correlational study in PA, USA, which compared the mental health of 315 husband and wife caregivers to recipients with Alzheimer disease. They investigated the differences in predictors of burden and depression between the two groups. Wives demonstrated higher burden scores and were more depressed than husbands. The researchers noted that the informal comments reported by the husbands expressed a greater sense of purpose in the caregiving experience. For example, "She took care of me when I

was ill, now it's my turn", or "She did everything for our family, now it's my turn to help" (p. 163). The spousal caregivers, in this sample, had attached meaning to the caregiving experience in different ways, thus affecting the reported level of burden. Further research into the meaning of caregiving was recommended.

Bowers (1987) conducted a qualitative study in the USA which used grounded theory to generate an intergenerational theory of caregiving. The author stated that the caregiving literature, which generally focused on the tasks of caregiving, was conceptually inadequate. Furthermore, it was recommended that the meaning or purpose which the caregiver attributed to the caregiving experience would be a more accurate representation of the caregiving experience. The sample consisted of 33 adult-child caregivers and 27 elderly care-recipients. Each subject was interviewed once and the length of the interviews ranged from 20 minutes to three hours, depending upon the subject's time restrictions and level of fatigue. The findings reported that caregiving was a very complex experience and was, surprisingly, unrelated to tasks. The meaning or purpose which the caregiver attributed to the experience was found to be a significant indicator of the consequences of caregiving. Any situation in the caregiving experience was found to be open to multiple, and often conflicting, meanings for different caregivers. For example,

preparing a meal was reported to have three meanings which were: (a) a gesture of caring; (b) a technical task; and (c) a combination of the two. Five conceptually distinct, but empirically overlapping, categories of caregiving were revealed. They were: (a) anticipatory, in which the caregiver based many life decisions on the potential needs of the parents; (b) preventative, which involved the caregivers actively monitoring or supervising the parent in an attempt to prevent illness or complications; (c) supervisory, which involved activities such as arranging for, checking out, verifying things for the care-recipient; (d) instrumental, which included the actual hands-on tasks of caregiving; and (e) protective, which involved protecting the care-recipient from threats to his/her self-image. This invisible shield that the caregivers placed around the care-recipients was seen as the most important type of caregiving to the caregivers. It was interesting to note that instrumental caregiving, which is the only observable type of caregiving and, consequently, the focus of most of the caregiving literature, was considered to be the least important to family caregivers. The other four categories were distinguished by their purpose and meaning, rather than task or time involvement.

Ross (1991) published a descriptive article which explored the experience of spousal caregiving in terms of its meaning, manifestations and consequences. Three meanings of

the experience were discussed. They were labour of love, reciprocity, duty and obligation. Ross, agreeing with Bowers (1987) contended that looking at the purpose of the caregiving experience, rather than the task-oriented approach, enabled an increased understanding of the caregiving experience. Bowers suggested that this focus in caregiving research would help to highlight the "invisible nature" of caregiving (p. 128).

Farran et al. (1991) echoed the increasingly felt need to explore the meaning and offered existentialism as a useful theoretical paradigm in this endeavour. The data for this study was taken from the results of a large longitudinal study of dementia family caregivers (n=94) in the Chicago metropolitan area. Both quantitative and qualitative data was obtained from the sample in a two hour structured home interview. The data was categorized into four themes. These themes were: (a) loss and powerlessness; (b) values, choices, provisional and ultimate meaning; (c) caregiving resources; and (d) responsibilities of caregiving. The discussion in the study focused on the first two themes, as the latter themes were reported to be very similar to the findings in the study by Bowers (1987). The results indicated that caregivers expressed existential themes in their description of the caregiving experience. The meaning of the experience was individual and, as such, not linked to race, gender, or relationship to the care-recipient. Also, the caregiver's personal choices affected his/her

attitude. This research supported existential theory as an appropriate theory to guide future caregiving research. Frankl (1963), the leading proponent of existential theory, was paraphrased by Farran (1991):

> Everything can be taken from the caregiver but the human freedom to choose his or her attitude in any given set of circumstances. This inner freedom determines whether a caregiver becomes a plaything of circumstances or an active participant in the caregiving situation. The sort of caregiver a person becomes is the result of an inner decision and not the result of the caregiving situation alone. Fundamentally, then, every caregiver can decide what will become of him-or-herself. (p. 485)

Measurement of Meaning

The Purpose-In-Life (PIL) was a 20-item instrument, rated on a 7-point Likert-type scale, which was developed as an attitude scale to measure the degree to which a person experienced a sense of meaning and purpose in life (Crumbaugh & Maholick, 1964). This tool was based on Viktor Frankl's concepts of existentialism. The researchers conducted a study to test the psychometric properties of the PIL. It was administered to 225 subjects who had been divided into two groups, patient and non-patient. Split-half reliability was

reported to be .81, corrected to .90 with Spearman-Brown formula. A positive correlation of .68 was reported with Frankl's concepts, attesting to a moderate degree of concurrent validity. The tool was discriminatory between the two categories of subjects and a significant correlation was reported with the Minnesota Multiphasic Personality Inventory (MMPI).

Crumbaugh (1968) conducted a study to gather quantitative evidence concerning the validity of Frankl's basic premise, which was that without 'meaning in life', man falls into an existential vacuum. The sample consisted of 1151 subjects in MI, who were divided into four 'normal' groups and six 'psychiatric patient' groups. The tool discriminated between the two categories of subjects, thereby supporting construct validity of the tool. Split-half (odd-even) correlation of the instrument resulted in a reliability co-efficient of .85, corrected by Spearman-Brown formula to .92, using 120 subjects from one of the 'normal' groups. This study supported the PIL as a reliable and valid tool which quantified Frankl's concepts.

Reker (1977) conducted an empirical investigation of the Purpose-in-Life (PIL) scale, which was devised to measure the degree to which meaning in life has been found. The sample consisted of 48 male inmates of a Canadian penitentiary. The study had three purposes: (a) to investigate the tool's

relationships with attitudes, locus of control, personality factors and demographic variables; (b) to assess the reliability and validity of the tool; and (c) to compare the scores of the inmate population with scores of non-inmate samples, that had been reported by other researchers. The results indicated that this instrument had sound psychometric properties. The split-half correlation yielded a co-efficient of .85, corrected by Spearman-Brown formula to .92. Other researchers (Crumbaugh, 1968; Reker & Cousins, 1979) have also acknowledged sound reliability for this scale.

Reker and Cousins (1979) investigated the validity of the PIL with a sample of 248 Canadian students. The researchers reported significant correlations with the Life At Present and Life In The Future scales, giving additional support to the validity of the tool. Split-half was reported to be .76, corrected to .87 with the Spearman-Brown co-efficient and the test-retest reliability, conducted on 31 students over six weeks, was reported to be .79.

A scale, which was complementary to the PIL, was developed by Crumbaugh (1977) to measure the strength of motivation to find meaning in life. It was called the Seeking of Noetic Goals Test (SONG). This tool consisted of 20-items, which were scored on a 7-point Likert scale from "never" to "constantly". This measure was found to be reliable in a study, by its author, using an American sample from a treatment

centre (n=158). The scale was found to discriminate between the population which had been categorized as 'normal' and 'abnormal'. There was a moderate negative correlation with the PIL, supporting its use as a complementary instrument.

The psychometric properties of the SONG were further researched by Reker and Cousins (1979) with a sample of 248 Canadian students. A stability co-efficient of .78 was reported and construct validity was established at that time.

Reker and Peacock (1981) built upon previous research and described the development of a multidimensional measure of attitudes toward life that was called the Life Attitude Profile (LAP). This tool included the two complementary dimensions of the PIL + SONG, both the motivation for finding meaning of life and the actual meaning that has been found. The results of the factor analytical study with a sample of 219 Canadian university undergraduates was a 56-item seven factored tool which accounted for 67% of the total variance. Internal consistency coefficients were satisfactory (.55 - .83). Construct validity was revealed using factor analysis. This tool, although psychometrically sound, was somewhat lengthy. Subsequently, a revision of this tool addressed these concerns (Peacock & Reker, 1982). The Life Attitudes Profile - Revised (LAP-R) resulted in improvements in the original LAP scale. Each of the 48-items was rated on a 7-point Likert scale of agreement, ranging from 'strongly agree' to 'strongly

disagree.' The scale retained six dimensions and offered two composite scales. The six dimensions were purpose, coherence, life control, death acceptance, existential vacuum, and goal seeking. The two composite scales were Personal Meaning Index (PMI) and Life Attitude Balance Index (LABI). The scale was reported to be psychometrically sound with internal consistent co-efficient ranging from .79 to .91 and stability ranging from .77 to .90 (Peacock & Reker, 1982; Reker, 1992). This scale has been used with samples ranging in age from 18-89 years (Tracy, 1992; Underhill, 1991) and has shown to be age-related. Older adults reported a higher sense of meaning, purpose, and greater death acceptance than middle-aged and younger adults. As well, older adults reported lower goal seeking and existential vacuum (lack of purpose).

The development of a measurement of meaning has been ongoing for over twenty years. The most recent being the LAP-R. This scale has been used in diverse Canadian samples and retained its psychometric properties.

Conceptual Model

Several nursing models (Benner, 1984; Neuman, 1989; Orem, 1985; Rogers, 1988; Roy, 1989; Watson, 1989) were reviewed in an attempt to locate an appropriate model to guide this investigation. None of the models that were reviewed captured

the concepts in this investigation in totality therefore, a conceptual model was created by the author. This framework demonstrated the relationships between the concepts that have been discussed in the current literature review and have theoretical roots in Frankl's (1963) philosophy of existentialism.

Viktor Frankl was a Jewish psychiatrist who was imprisoned by the Germans in concentration camps during World War II. Throughout his incarceration he made observations which became the basis of his philosophy. The basic premise of existentialism was: to live is to suffer, to survive is to find meaning in the suffering (Frankl, 1963, p. xi). Suffering was a part of life and it was individual actualization of the suffering that affected his/her meaning of life at that time (Frankl).

Frankl (1963) drew on the following analogy of gas particles in a chamber to demonstrate the relative nature of suffering. No matter how many gas particles were in the chamber, they effectively filled the chamber by distributing themselves evenly. Therefore, one could judge another's suffering by the number of particles in his/her chamber. What determined the amount of suffering or burden that was experienced by the individual was the attitude that he/she assumed toward the suffering. Each person's "unique opportunity lies in the way he/she bears his/her burden" (p. 78). When an

individual was confronted with an unavoidable situation, he/she retained the ability to choose his/her attitude toward the circumstances. It was this choice which offered a person the opportunity to transcend the situation and derive meaning from it. "Suffering ceases to be suffering the moment it finds meaning and it is man's ultimate goal to see meaning in his life" (p. 115). "He/she who has a **why** to live can bear with almost any **how**" (p. 76).

This philosophy was relevant to the caregiver in society (Farran, 1991). It helped to explain individual responses to caregiving that have been documented in the literature. The amount of caregiver burden that the caregiver experienced would be related to his/her derived meaning of the situation, according to this philosophy.

The investigator would like to suggest an alternative model involving a third variable, psychological well-being. Jobson (1991) and Miller (1990) suggested that psychological well-being can be viewed as a personality trait, stable over time, and not as a fluctuating state within an individual. Building on this suggestion, it is plausible that this trait could be directly related to one's meaning. If one views caregiver burden as a situational outcome, a new model might be suggested with psychological well-being mediating between meaning and caregiver burden. Evidence was found in the literature to support this alternative model. The results of

a study by Pagel and Becker (1987) suggested that personality factors were predictive of depression. A study by Pruchno, Kleban, Michaels and Dempsey (1990) found psychological well-being predictive of caregiver burden.

The present conceptual model for the investigation depicts the relationship between the concepts that have been identified: meaning, psychological well-being, and caregiver burden. Meaning influences psychological well-being, which impacts on caregiver burden. Uni-directional arrows represent the linkages between these concepts. Caregiver characteristics, including demographics and items regarding length of illness etc., are included in the model to explore the relationship among the variables. This investigation will explore the relationships depicted in Figure 1.

Definition of Terms

The following concepts will be defined for the investigation: (a) informal caregiver; (b) characteristics of the caregiver such as age, gender, income; (c) psychological well-being of the caregiver; (d) meaning; (e) caregiver burden; and (f) recipient of care.

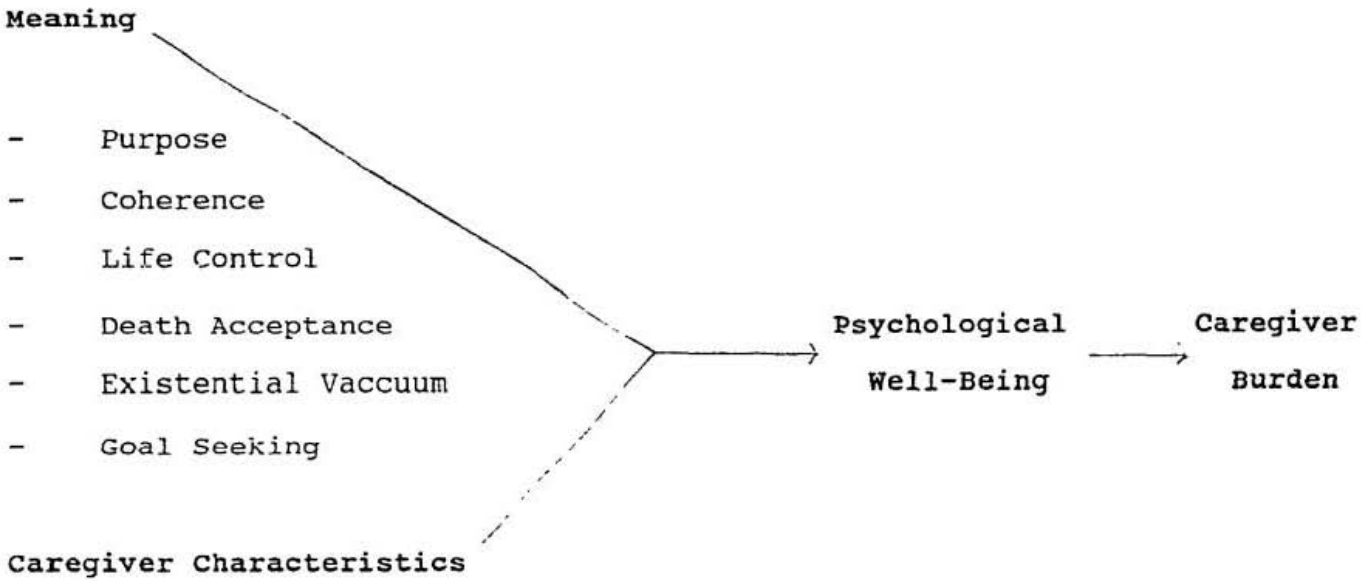

Figure 1. Relationships Among the Variables in the Model

The definitions are:

Informal Caregiver has been identified in the literature as one who is unpaid for his/her services (Poulshock & Deimling, 1984). The operational definition was a spouse, adult child or other family member who was self-identified as the main provider of support (i.e. emotional, financial, task-oriented etc.) for the institutionalized Alzheimer patient. This individual must have attained a minimum grade V education in order to meet the criteria for completion of the LAP-R (Reker, 1992).

Characteristics of the Caregiver were defined as indicated by respondent. Income will be operationalized as the total net income of the household.

Psychological Well-Being of the Caregiver was defined as the "presence of positive emotions, such as happiness, contentment, joy, peace of mind, and the absence of negative emotions such as fear, anxiety, and depression" experienced by the caregiver (Reker & Wong, 1984, p. 24). This was operationalized by the respondent's score on the Memorial University of Newfoundland Scale of Happiness (Stones & Kozma, 1989).

Meaning referred to one's drive to create meaning in one's life. This urges an individual onwards to choose one's attitude towards a circumstance, even though situational restraints existed (Frankl, 1963). Attitude referred to "opinions, views and dispositions representing a generalized

set of values toward classes of objects" (Allport, 193[illegible] cited in Corsini, 1977, p. 3). Life attitudes were based on the existential premise that man had a:

> ... universal-unlearned human ability to perceive specific meanings in the world of events and to transcend any concrete situation on the basis of that attributed meaning. This concept associated with a unique individual was a kind of recognizable meaning matrix which, when imposed on reality, allowed the distinctive style and life direction of the person to emerge. It was this concept which underlies his choices and gives them particular form. (Binswanger, 1963, p. 246)

The meaning of the life experience was operationalized by the subject's response on six dimensions (purpose, coherence, life control, death acceptance, existential vacuum, goal seeking) of the Life Attitudes Profile-Revised (Reker, 1992).

Caregiver Burden was defined as the changes that occur in the physical, emotional, developmental, social and time dependence dimensions of the caregiver's lives as a consequence of the caregiving role (Novak & Guest, 1989). The operational definition of this concept was the subject's response on the Caregiver Burden Inventory (Novak & Guest, 1989).

Recipient of Care was an individual who had a medical diagnosis of Alzheimer disease and had been institutionalized for a minimum of six months

Summary

A review of the literature has been presented, followed by a conceptual model depicting the relationships among the major variables in the investigation. Definition of terms was presented. The major points from the literature review will be highlighted. They were: (a) caregiver burden is a multidimensional concept of great complexity; (b) the prevalence and incidence of Alzheimer disease is increasing in the Canadian population; (c) caregivers are predominately female and the selection process follows a hierarchal ordering of spouse, adult-child, other; (d) age of the caregiver is inversely related to burden; (e) females report, overall, higher levels of caregiver burden; (f) caregiver burden is described by caregivers in all living arrangements and the closer the proximity of living arrangement, the higher the level of burden; (g) financial duress increases the level of burden; (h) the relationship (spouse/adult-child/other) of the caregiver to the recipient impacts on the level of burden experienced; (i) caregiver's psychological well-being is generally lower than the population norm; (j) meaning has been taking on

increasing importance in the caregiving literature; and (k) meaning appears to affect level of caregiver burden.

CHAPTER III

Methodology

The purpose of this investigation was: (a) to describe a sample of informal caregivers whose recipient of care was an institutionalized Alzheimer patient; and (b) to determine the relationships between meaning, psychological well-being, and caregiver burden for this sample. This section will present a description of: (a) the research design; (b) setting; (c) the sample and selection of subjects; (d) data collection procedures used in the investigation; (e) ethical considerations; (f) instrumentation; (g) pre-test; (h) data analysis; and (i) limitations of the investigation.

Research Design

Although previous studies presented in the literature review used descriptive, correlational or causal comparative design, this investigation used a descriptive exploratory design which allowed the purpose of the study to be fulfilled. This type of research design investigated the relationships between the selected variables.

Setting

Data collection was conducted in the caregiver's home with only the researcher and the subject present in the room. Any extraneous noise (i.e. from the radio/television) was eliminated. This ensured privacy and avoided distraction, facilitating the rapport between the researcher and subject.

Sample and Selection of Subjects

The target population for this investigation was 45 informal caregivers of institutionalized Alzheimer patients who had been institutionalized for a minimum of six months. The sample was one of convenience. This population was accessed through four institutions in the St. John's area. Table 1 presents a breakdown of the sample by institution. Informal preliminary contact was made with each of these facilities and they expressed interest in performing an intermediary role in this research investigation. Their participation was formally established after the ethical review process. Inclusion criteria for the sample included: (a) the informal caregiver must have Grade 5 education in order to meet the criteria to complete the Life Attitude Profile-Revised; and (b) the care-recipient must be diagnosed

Table 1

Breakdown of the Sample by Institution (n=45)

Institution	Frequency	Percent
Institution A	15	33.3
Institution B	16	35.6
Institution C	10	22.2
Institution D	4	8.9

with Alzheimer disease and have been institutionalized for a minimum of six months. All caregivers of care-recipients who met inclusion criteria were contacted and those who agreed to participate became subjects for the investigation. Factors which may have influenced potential subject's willingness to participate may have included: (a) intermediary contact's presentation; (b) potential subject's attitude towards institution; and (c) time of day. Interviews with subjects occurred over a six week period of time.

Procedure

A letter (Appendix A) was sent to each facility, requesting formal consent for participation in the investigation. The participation of the facility involved acting as an intermediary between the researcher and potential subjects. Upon receiving formal consent to participate from each facility, each institution compiled a list of all the subjects meeting the criteria for the investigation. Two facilities forwarded a letter (Appendix B) to prospective subjects inviting them to participate in the investigation and directing individuals to return the self-addressed stamped envelope in the mail if they wished the researcher to contact them. Two facilities telephoned the list of prospective subjects and, after obtaining permission from the potential subject, provided this

list to the researcher. All potential subjects who had sent a response to the investigator, as well as, those names on the lists provided by the institutions were telephoned by the investigator to: (a) establish interest; (b) validate their role as caregiver to an institutionalized Alzheimer patient; (c) ensure that inclusion criteria was met; and (d) set up an interview time that was mutually convenient. Verbal consent was attained at this time. Written consent (Appendix C) was obtained at the beginning of the home interview, prior to the collection of data. The interview time ranged from 45 minutes to 1-1/2 hours. Four questionnaires were administered to all the subjects in the same order. They were: (a) the demographic sheet (Appendix D); (b) the Life Attitudes Profile-Revised (Appendix E); (c) the Memorial University of Newfoundland Scale of Happiness (Appendix F); and (d) the Caregiver Burden Inventory (Appendix G). Permission to use these instruments is shown in Appendices H, I, J, respectively. Although the exact number of potential subjects who declined to participate in the investigation was unobtainable for the researcher, the persons making initial contact approximated that 66% of the potential subjects consented to be interviewed.

Ethical Considerations

Borg and Gall (1989) claimed that the ethical concerns of a study referred to the respect and concern for the dignity and welfare of the subjects. This investigation, which was approved by the Health Sciences Human Investigations Committee (HIC), invited subject participation. An informed written consent (Appendix C) was obtained at the beginning of the interview. All risks and benefits were explained to participants. Anonymity of the subject was explained to the subject and was protected by using a coding scheme for the names of the participants. The code book was kept in a locked safe which could only be accessed by the researcher.

Instrumentation

The investigation used the following instruments: (a) the demographic sheet (Appendix D); (b) the Life Attitudes Profile-Revised (Appendix E); (c) the Memorial University of Newfoundland Scale of Happiness (Appendix F); and (d) the Caregiver Burden Inventory (Appendix G). These instruments were administered in the above order to all subjects. This order was established by the researcher to maintain: (a) consistency of data collection; and (b) progression from general to specific questions.

Demographic Data

Specific items were included on the demographic data sheet to afford a comprehensive picture of the caregiver and the caregiving role. Items (i.e. age, sex, marital status) described the characteristics of this caregiver population. Other items (i.e. number of visits per month, quality of relationship, adequacy of support) were selected from the literature and provided additional information about the caregiver and his/her caregiving role. Collectively, this information enhanced the understanding of this caregiver population.

Life Attitudes Profile - Revised (LAP-R) (Reker, 1992)

This tool, which has Existentialism as its theoretical framework, was congruent with this investigation on meaning. It was a self-report instrument, composed of 48-items in six dimensions (Purpose, Coherence, Life Control, Death Acceptance, Existential Vacuum, Goal Seeking) and two composite scores (Personal Meaning Index (PMI) and Life Attitude Balance Index (LABI)). The six dimensions of life attitude were: (a) purpose (pu) which referred to having life goals and a sense of direction from the past, present and future in life (Reker, 1992); (b) coherence (co) referred to a sense of personal identity and understanding of self, others and life in general (Reker, 1992); (c) life control (lc) referred to the percep-

tion of having control over one's life (Reker, 1992); (d) death acceptance (da) referred to the acceptance of death as a natural part of life without fear (Reker, 1992); (e) existential vacuum (ev) referred to a lack of meaning and direction in life (ie. a frustrated "will to meaning") (Reker, 1992); and (f) goal seeking (gs) referred to a desire to seek challenge and to get more out of life (Reker, 1992). The two composite scales were newly devised and were not used in this investigation. The six dimensions reported internal consistency co-efficients ranging from .79-.91 and test-retest (at 4-6 weeks) reliability ranging from .77 - 90. Construct and concurrent validity of this instrument was reported by Reker (1992). The tool is rated on a 7-point Likert scale, ranging from 1 'strongly disagree' to 7 'strongly agree'. The scores range from 8 - 56 for each subscale and the attainment of that particular attribute is reflected by a high score in the subscale. The tool has been used in diverse populations (Reker, 1992). This tool was chosen because of its sound psychometric properties, congruency to the theoretical perspective of the investigation, varied and diverse usage, and Canadian orientation.

Reliability of the LAP-R in the investigation.

The reliability of the LAP-R was established using Cronbach's alpha. The alpha coefficients that were obtained

for the LAP-R subscales ranged from .65 to .88. An alpha coefficient of .24 was reported in one of the subscales (PMI). Based on this result, and with the advice of a statistician a decision was made to omit the two composite scores (PMI and LABI) from subsequent analysis. Therefore, six subscales of the instrument (CO, PU, LC, EV, DA, GS) were used in data analysis.

Memorial University of Newfoundland Scale of Happiness (MUNSH) (Stones & Kozma, 1989)

Memorial University of Newfoundland Scale of Happiness (MUNSH), which measures both the positive and negative aspects of psychological well-being, was used to index the caregiver's psychological well-being. The focus of this investigation involved the meaning, therefore it was conceivable that the caregiving experience may have had positive consequences for some. This instrument was used to discover the degree of happiness/depression that the experience had brought to the informal caregiver. The 24-items in the instrument included: (a) five items reflecting positive affect; (b) five items reflecting negative affect; (c) seven items reflecting general positive experience; and (d) seven items reflecting negative experience. The wording of the items was easily understandable and the dichotomous scoring further simplified its administration. The MUNSH was chosen to be used in this investigation

because of strong psychometric properties, ability to measure both positive and negative aspects of psychological well-being, Canadian orientation, and use in diverse populations.

Reliability of the MUNSH in the investigation.

The reliability of the MUNSH was established using Cronbach's alpha. The alpha coefficient for the instrument was .90.

Caregiver Burden Inventory (Novak & Guest, 1989)

Caregiver Burden Inventory (CBI) was a 24 item scale which had five factors. The five factors were: (a) time dependence burden which referred to the restrictions on the caregiver's time because of the caregiving role; (b) developmental burden which described the caregiver as being "off-time" in their development with respect to their peers; (c) physical burden which was defined as changes in the caregiver's health that were attributed to the caregiving role; (d) social burden which explored the caregiver's feelings of role conflict; and (e) emotional burden which defined the caregiver's negative feelings toward the caregiving experience. The authors reported an internal consistency reliability ranging from .73 - .86 for the five factors. It was scored on a 5-point scale ranging from 0 = 'not at all descriptive' to 4 = 'very descriptive'. Each dimension may yield a score ranging from 0 - 20, when factor 3 scores are multiplied by

1.29. The scale was specific for caregivers of individuals with Alzheimer disease. It is of Canadian orientation and has been used with caregivers of non-institutionalized and institutionalized populations (Novak & Guest, 1989). Although this tool was relatively new and has had limited use, the author selected it because of its applicability for the Canadian caregiver of the institutionalized Alzheimer patient and ability to profile the dimensions of caregiving.

Reliability of the CBI in the investigation.

The reliability of the CBI was established using Cronbach's alpha. The reliability scores for the five subscales and composite score of this instrument ranged from .47 to .85. The reliability scores for all the instruments and their subscales used in the investigation are displayed in Table 2.

Table 2

Cronbach's Alpha Reliability Scores for Investigation Instruments

Instrument		Intercorrelation Between Subscales
Life Attitude Profile-Revised (LAP-R)		
Subscales:	Purpose	.76
	Coherence	.66
	Life Control	.65
	Death Acceptance	.88
	Existential Vacuum	.77
	Goal Seeking	.82
Caregiver Burden Inventory (CBI)		.85
CBI Subscales:	Time Dependence Burden	.74
	Developmental Burden	.84
	Physical Burden	.85
	Social Burden	.47
	Emotional Burden	.72
Memorial University of Newfoundland Scale of Happiness (MUNSH)		.90

Pre-Test

A pre-test was conducted with four caregivers who were representative of the study population. Based on the results, modifications were made to the instruments which would not violate their psychometric properties. They were: (a) formatting changes which reduced the number of pages to be administered to each subject; and (b) changes in the demographics sheet that facilitated the subject's accurate response. The pre-test was conducted within the estimated time frame and indicated that, in general, the subjects understood the questions.

Data Analysis

The following data analysis was conducted. Statistical analysis of the data used the Statistical Package for Social Sciences (Nie, Hull, Jenkins, Steinbrenner & Brent, 1982) computer program. Upon consultation with a statistician, both descriptive and inferential statistics were used to answer the research questions.

Descriptive statistics were used to describe the caregiver characteristics including: age, sex, marital status, length of time care-recipient had been institutionalized, educational level of caregiver, relationship to care-recipi-

ent, length of care-recipient's illness, quality of relationship with care-recipient, adequacy of caregiver's support (including information about support groups), income of the caregiver. As well, descriptive statistics were completed on meaning, psychological well-being, and caregiver burden. Qualitative data concerning visits with the care-recipient was collected.

Throughout the data analyses, significant findings were reported at the .05 level. Cronbach's alpha was chosen to measure the internal consistency of the instruments: Life Attitude Profile - Revised (LAP-R), Memorial University of Newfoundland Scale of Happiness (MUNSH), and Caregiver Burden Inventory (CBI).

One-way analyses of variance compared the sample means for selected caregivers characteristics, meaning, psychological well-being, and caregiver burden by institutions for homogeneity of the sample. A Scheffe test was conducted on the results for purpose of multiple comparison. A Pearson product-moment correlation matrix was created to identify relationships between the caregiver characteristics, subscales of the LAP-R (PU, CO, LC, EV, DA, GS), subscales of the CBI, and MUNSH.

Based on the relationships found in the correlational matrix, stepwise multiple regression was conducted to explore the model. According to Burns and Growe (1993), the initial

phase of stepwise multiple regression enters the independent variable which has the highest correlation with the dependent variable. Then the program computes semi-partial correlations for the remaining independent variables, eliminating the effects of the entered variable. If any remaining semi-partial correlations are significant, the highest correlation with the dependent variable will enter on step two. Semi-partial correlations are computed for the remaining variables with the effects of entered variables removed. This process will continue until no more semi-partial correlations are significant and no more variables enter the equation. The semi-partial correlations are reported in a standardized form given by the Beta which will be reported. When this procedure takes account of the relationships within an array of independent variables where the sample size is greater than 25 and the ratio of variables that enter the equation to subjects is 8 - 12: 1, the Beta is regarded as robust (Jobson, 1991; Miller, 1990). According to Borg and Gall (1989), the results of the multiple regression analysis will determine the best predictor of the dependent variable and the amount of variance accounted.

In view of the low internal consistency of one of the subscales in the CBI and upon consultation with a statistician, it was decided that subsequent analyses would only use the composite score of the CBI. The first stepwise multiple

regression was conducted with the composite score of Caregiver Burden Inventory as the dependent variable and selected caregiver characteristics, subscales of the LAP-R, and MUNSH as independent variables. Based on the results of the first regression analysis, selected caregiver characteristics, and subscales of the LAP-R were entered as independent variables, with the MUNSH as the dependent variable.

Limitations of Investigation

The limitations in this investigation were: (a) the blending of spousal, adult child and relative caregivers together may have obscured differences between the groups; and (b) certain variables, such as length of caregiving, level of impairments of recipient were not addressed. This may have impacted upon both the caregiver's life attitudes and his/her level of reported burden; and (c) use of a convenience sample from several institutions in the Newfoundland elderly population who are caregivers to an Alzheimer population. This limited generalizability of results.

CHAPTER IV

Results of the Investigation

This descriptive, exploratory investigation was conducted on a sample of 45 informal caregivers of persons who had been institutionalized for Alzheimer disease for a minimum of six months. Purposes of this investigation were to: (a) to describe a sample of informal caregivers whose recipient of care was an institutionalized Alzheimer patient; and (b) to explore the relationships between caregiver burden, meaning, and psychological well-being for this sample. The results of the investigation will be presented in the following two major sections: (a) characteristics of the sample; and (b) relationships among selected caregiver characteristics, meaning, psychological well-being, and caregiver burden.

Characteristics of the Sample

Sample

The first research question will be answered using the following results. Characteristics of the sample are displayed in Table 3. Of the sample of 45 informal caregivers, 67% were female and 33% were male. The age range was 27 - 92 years with

Table 3

Characteristics of the Sample (n=45)

Variable	Category	Frequency	Percent
Sex	Female	30	67
	Male	15	33
Age	25 - 44	8	17
	45 - 64	22	49
	65+	15	34
Marital Status	Married	36	80
	Single	4	9
	Divorced	2	4
	Widowed	2	4
	Separated (legally)	1	2
Relationship of Respondent to Care-Recipient			
	Daughter	18	40
	Spouse	10	22
	Other	9	20
	Son	8	18
Education Level (attained)			
	Post-Secondary	28	62
	Grade 12 or Equivalent	10	22
	Grade 5	7	16
Perception of Quality of Relationship			
	Excellent	26	58
	Very Good	9	20
	Good	7	16
	Fair	3	7
	Poor	0	0
Perception of Adequacy of Support			
	Excellent	14	31
	Very Good	13	29
	Good	10	22
	Fair	3	7
	Poor	5	11

(table continued)

Variable	Category	Frequency	Percent
Member of Alzheimer Support Group			
	No	36	80
	Yes	9	20
Attendance at Alzheimer Support Group Meetings			
	Never	29	64
	Sometimes	14	31
	Always	2	4
Income of Respondent			
	$10,000 - $19,999	7	17
	$20,000 - $29,999	8	19
	$30,000 - $39,999	5	12
	$40,000 - $49,999	6	14
	$50,000 - $59,999	7	17
	$60,000 +	9	21
	No response	3	7
Time Spent at Average Visit			
	1 - 2 hours	29	64
	< 1 hour	10	22
	> 2 hours	6	13
Activities During Visit			
Walk	No	29	64
	Yes	16	36
Talk	Yes	45	100
	No	0	0
Feeding	No	29	64
	Yes	16	36
Show Affection	Yes	32	71
	No	13	29
Bath Care-Recipient			
	No	44	98
	Yes	1	2
Other (i.e. look at pictures)			
	Yes	29	64
	No	16	36

a mean age of 59 years. All caregivers were white. The majority were married (80%). The majority of the sample (62%) had completed some form of post-secondary education. Eighty-two percent of the sample reported good to excellent social support. Twenty per cent reported that they were members of an Alzheimer support group, yet only 4% of the sample consistently attended Alzheimer Support Group meetings.

The relationships between the caregiver and the care-recipient varied but the majority were daughters (40%). The majority of the sample (58%) reported their relationship with the care-recipient to be excellent. The median for the length of the care-recipient's illness was 72 months. The length of time that the care-recipient had been institutionalized ranged from 6 months to 6 1/2 years with a median of 24 months. The average visit occurred 12 times per month and lasted between 1 - 2 hours. When the respondents were asked to describe a typical visit, six categories of activities emerged. They were: (a) walking (36%); (b) talking 100%; (c) visiting during meal time, but not feeding (64%); (d) showing affection (71%); (e) bathing (2%); and (f) other (64.%), such as having tea with spouse and looking at pictures.

Within Sample Variability

The results of one-way analyses of variance by institutions found two statistically significant differences in the

sample means. They were on income ($p < .01$) and life control ($p < .03$). The Scheffe procedure was conducted on income by institution and statistically significant different group means were found between Institution A and Institution B. The Scheffe procedure was conducted on life control by institution and statistically significant different group means were found between Institution C and Institution B. No statistically significant differences in the sample means were found for psychological well-being or caregiver burden among the institutions. The results are shown in Appendix K.

Meaning of the Caregiving Experience

The instrument that was used to describe meaning was the Life Attitude Profile-Revised (LAP-R) which is comprised of six subscales: Purpose (PU), Coherence (CO), Life Control (LC), Death Acceptance (DA), Existential Vacuum (EV), Goal Seeking (GS). The scores on each subscale have a range of 8 - 56, with a high score reflecting the attainment of a high degree of the attribute. The second research question will be answered using the following results. The frequency distribution of the LAP-R scores of the sample by subscale are shown in Appendix L. The mean, standard deviation and range of scores for subscales of LAP-R are shown in Table 4.

Table 4

Mean, Standard Deviation, Range of Scores on Life Attitude Profile - Revised (LAP-R), Psychological Well-Being (MUNSH), Caregiver Burden (CBI)

Scale	Mean	Median	Standard Deviation	Range of Scores
LAP-R				
Purpose	23	21	6.7	11 - 39
Coherence	20.7	21	5.7	12 - 38
Life Control	19.2	20	6.1	10 - 36
Death Acceptance	21.6	20	9.4	8 - 46
Existential				
Vacuum	39.4	42	8.4	19 - 51
Goal Seeking	29.4	28	9.0	10 - 47
MUNSH	12.5	16	10.4	-16 - 24
CBI	21.6	18	13.8	0 - 53
Time	6.2	5	4.5	0 - 16
Developmental	7.3	6	5.5	0 - 20
Physical	4.1	2.5	5.3	0 - 18.8
Social	3.2	2.5	3.3	0 - 13
Emotional	1.6	1.0	2.8	0 - 16

Psychological Well-Being

Psychological well-being of the caregiver was measured using the Memorial University of Newfoundland Scale of Happiness (MUNSH). The third research question will be answered using the following results. In this investigation, the scores ranged from a minimum of -16 to a maximum of 24, with a mean of 12.5, a median of 16 and a standard deviation of 10.4. The frequency distribution of the MUNSH scores are shown in Appendix M. Mean, median, standard deviation, range of scores for the MUNSH are shown in Table 4.

Caregiver Burden

The Caregiver Burden Inventory (CBI) was used to describe the level of burden experienced by the caregivers in the investigation. The minimum total score possible is 0 and the maximum total score possible is 100. The following results will be used to answer research question four. In this investigation, the range of scores was from a minimum of 0 to a maximum of 53, with a median of 18, a mean of 22, and standard deviation of 13.9. The frequency distribution of total scores and subscales of the CBI are outlined in Appendix N. The results of the mean, median, standard deviation and ranges for Caregiver Burden Inventory are shown in Table 4.

Relationships Among Caregiver Characteristics, Meaning, Psychological Well-Being, and Caregiver Burden

In order to answer research question five, a correlational matrix was created and causal pathways explored. The correlation matrix identified relationships between the variables in the investigation. The following variables were entered in the Pearson product-moment correlation matrix: selected caregiver characteristics (age, sex, marital status, length of institutionalization, relationship, education, length of care, quality of relationship, adequacy of support, income, # of visits, length of visits), subscales of Life Attitude Profile - Revised (LAP-R), Memorial University of Newfoundland Scale of Happiness (MUNSH), and Caregiver Burden Inventory (CBI). Although it was recognized that one of these subscales of Caregiver Burden Inventory (Social Burden) had low internal consistency (refer to Table 2, page 83) and results from this scale must be viewed with caution, all subscales and the composite score of CBI were entered for inclusiveness and detail. In view of the low internal consistency of one of the subscales of the CBI and upon consultation with a statistician, it was decided that subsequent analyses would only use the composite score of the CBI. The correlation matrix is shown in Table 5.

Table 5

Correlational Matrix Showing Correlational Coefficients Between Variables in the Investigation: Caregiver Characteristics, Meaning, Psychological Well-Being and Caregiver Burden

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)
Psychological Well Being (1)	1.00	-.07	-.62**	-.55**	-.56**	-.30*	-.64**	-.66**	08	-.38**	-.05	.60**	-.02
Time Dependence Burden (2)		1.00	32*	28	.04	15	58**	04	-.02	-.08	16	.05	.15
Developmental Burden (3)			1.00	52**	.32*	59**	83**	47**	21	.17	-.06	-.41**	08
Physical Burden (4)				1.00	46**	37*	79**	38*	-.04	24	10	-.43**	11
Social Burden (5)					1.00	31*	57**	36*	14	33*	13	-.45**	-.05
Emotional Burden (6)						1.00	58**	20	-.19	05	-.23	-.15	21
Composite Burden Score (7)							1.00	44**	-.10	21	05	-.42**	14
Purpose (8)								1.00	14	7**	37*	-.32*	33*
Coherence (9)									1.00	42**	25	.14	17
Life Control (10)										1.00	46**	-.17	27
Death Acceptance (11)											1.00	.07	2*

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)
Existential Vacuum (12)												1.00	.37*
Goal Seeking (13)													1.00
Age (14)													
Sex (15)													
Marital Status (16)													
Length of Institutionalization (17)													
Relationship to Care-Recipient (18)													
Education Level (19)													
Length of Illness (20)													
Quality of Relationship (21)													
Adequacy of Support (22)													
Income (23)													
Number of Visits (24)													
Length of Visits (25)													

*p< .05 **p<.01

Results rounded to two decimal points.

Table 5 (continued)

Correlational Matrix Showing Correlational Coefficients Between Variables in the Investigation: Caregiver Characteristics, Meaning, Psychological Well-Being and Caregiver Burden

Variables	(14)	(15)	(16)	(17)	(18)	(19)	(20)	(21)	(22)	(23)	(24)	(25)
Psychological Well Being (1)	- 30*	23	.14	- 21	-.02	42	-.51**	09	40**	49**	- 23	-.28
Time Dependence Burden (2)	0 23	08	-.27	- 24	- 22	.17	.12	- 04	-.00	.29	22	39
Developmental Burden (3)	32*	-.10	- 21	03	02	-.29	.42**	- 07	- 16	-.23	28	.26
Physical Burden (4)	.03	- 06	- 15	06	- 03	- 07	49**	-.28	- 44	- 23	- 09	15
Social Burden (5)	-.05	03	-.12	17	-.08	- 11	30*	- 16	- 39*	-.31*	17	06
Emotional Burden (6)	33*	13	- 05	06	06	05	09	- 13	- 12	- 16	- 02	- 08
Composite Burden Score (7)	11	- 01	- 26	.00	- 08	- 10	45**	- 19	- 32*	- 17	20	3**
Purpose (8)	06	06	- 24	07	08	- 21	33*	- 16	- 10	- 21	15	36*
Coherence (9)	- 3**	- 02	- 29	37*	03	*5	22	0 7	- 09	17	04	- 10
Life Control (10)	- 09	*3	- *6	*6	04	02	34*	- *8	00	- *2	08	24
Death Acceptance (11)	- 26	05	- 32*	- 09	09	24	- 03	06	24	- 00	27	28

Variables	(14)	(15)	(16)	(17)	(18)	(19)	(20)	(21)	(22)	(23)	(24)	(25)
Existential Vacuum (12)	- 09	33	18	- 11	- 07	34*	- 31	09	47**	44**	08	- 06
Goal Seeking (13)	26	07	- 23	- 16	27	-.03	- 08	- 25	10	12	19	15
Age (14)	1 00	- 22	16	10	49**	- 44**	- 07	- 10	- 00	- 41**	08	- 10
Sex (15)		1 00	25	- 21	- 23	25	-.08	- 03	09	.12	04	.29
Marital Status (16)			1.00	- 00	.06	-.05	- 22	- 20	- 05	04	- 08	-.16
Length of Institutionalization (17)				1 00	20	- 15	43**	.08	29	- 37*	- 21	- 19
Relationship to Care-Recipient (18)					1 00	-.25	- 06	-.12	09	-.23	-.04	-.23
Education Level (19)						1.00	- 23	.15	.34*	.42**	-.01	-.26
Length of Illness (20)							1.00	-.10	-.45**	-.27	-.08	.24
Quality of Relationship (21)								1.00	.40**	.08	.22	- 07
Adequacy of Support (22)									1 00	.43**	.21	-.07
Income (23)										1.00	.10	-.08
Number of Visits (24)											.100	.10
Length of Visits (25)												1.00

*p< .05 **p<.01

Results rounded to two decimal points.

Exploration of Causal Pathways in the Investigation

In order to further explain the relationships among selected caregiver characteristics, meaning, psychological well-being, and caregiver burden, two stepwise multiple regressions were performed. The use of this method enabled more than one independent variable to be used at any one time, affording a more complete explanation of the dependent variable. The first stepwise multiple regression was conducted to identify which variables best predicted caregiver burden. In view of the low internal consistency of one of the subscales of the CBI and upon consultation with a statistician, it was decided that subsequent analyses would only use the composite score of the CBI. The variables that were considered for inclusion were: selected caregiver characteristics (age, sex, marital status, length of institutionalization, relationship, education, length of care, quality of relationship, adequacy of support, income, # of visits, length of visits), meaning, and psychological well-being. Psychological well-being was identified as the only significant predictor of caregiver burden beyond the .05 level of significance with a beta value of -.63. The ratio of subjects to variables that entered the equation was high - 45 : 1. The impact of psychological well-being on burden yielded: $F(1, 43) = 27.98$, $p < .001$. This indicated that the amount of per-

ceived burden was dependent upon an individual's level of depression. Depression accounted for 39.4% of the variance in caregiver burden. Results are shown in Table 6.

Psychological well-being was the only predictor of caregiver burden. To further quantify the relationships between the variables, a second stepwise multiple regression was conducted with psychological well-being as the dependent variable. The variables that were considered for inclusion were selected caregiver characteristics (age, sex, marital status, length of institutionalization, relationship, education, length of care, quality of relationship, adequacy of support, income, # of visits, length of visits) and meaning. Purpose (subscale of meaning) entered on step one of the equation, indicating that it was the best predictor of depression. The impact of purpose on psychological well-being reported $F\ (1, 43) = 32.83$, $p < .001$ and accounted for 43.2% of the variance. Six variables reached significance in the regression procedure. They were: Purpose, Existential Vacuum, age, length of caregiving, number of visits, relationship to care-recipient, respectively. The ratio of subjects to variables that entered the equation was approximately 8 : 1. These six variables yielded $F\ (6, 38) = 23.41$, $p < .001$ and accounted for 78.7% of the variance in psycho-logical well-being. The results are shown in Table 7.

Table 6

Stepwise Multiple Regression For Psychological Well-Being, Meaning, Selected Caregiver Characteristics By Caregiver Burden (Dependent Variable)

Independent Variables	Beta	Significance
Psychological Well-Being	-.6278	.000***

*** p < .001

Table 7

Stepwise Multiple Regression For Meaning, Selected Caregiver Characteristics By Psychological Well-being (Dependent Variable)

Independent Variables	Beta	Significance
LAP-R Subscales:		
Purpose	-.61	.00***
Existential Vacuum	.47	.00***
Caregiver Characteristics:		
Age	-.25	.00***
Length of Illness	-.07	.00***
Number of Visits	-.21	.02*
Relationship to Care-Recipient	.18	.04*

* $p < .05$ *** $p < .001$

Conceptual Model

The analyses in this investigation have specified statistically significant relationships between the following variables: selected caregiver characteristics, meaning, psychological well-being, and caregiver burden. According to the empirical data, psychological well-being was the only predictor of caregiver burden. This investigation established a linear relationship between psychological well-being and caregiver burden. The next step was to ascertain the predictor/s of psychological well-being. Subsequent analysis established the relationship between selected caregiver characteristics, meaning and psychological well-being. Meaning (specifically, purpose and existential vacuum, which is lack of purpose) impacted on and were the best predictors of psychological well-being. A linear relationship had been found between the variables in the following order: meaning (specifically, purpose and existential vacuum), psychological well-being, and caregiver burden. Also, four caregiver characteristics were predictive of psychological well-being: age, length of illness, number of visits, and relationship to caregiver. The predictive model is shown in Figure 2.

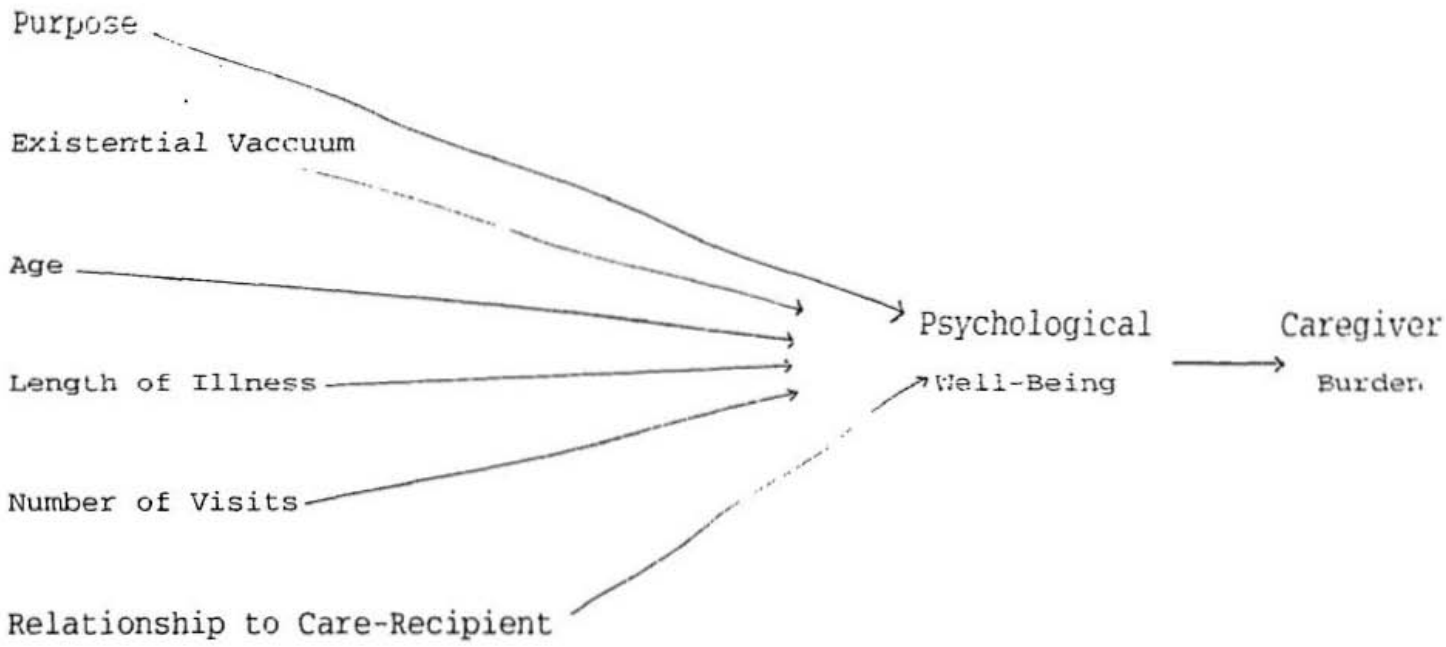

Figure 2. Conceptual Model Showing Predictive Nature Among the Variables in the Investigation

Summary of Results

This investigation found that the sample was similar across the institutions. Therefore, subsequent statistical procedures were performed on the complete sample. The results of the statistical analyses were reported in the following categories: characteristics of the sample, relationships among the variables in the investigation, exploration of causal pathways, and a predictive model. These results have provided the basis for answers to the research questions and identified a path model. The following section will discuss the results, refer to the research questions, and offer an interpretation.

CHAPTER V

Discussion

The purpose of this investigation was to: (a) describe a sample of informal caregivers whose recipient of care was an institutionalized Alzheimer patient; and (b) explore the relationships between selected caregiver characteristics, meaning, psychological well-being, and caregiver burden for this sample. The following section will address this purpose, specifically discussing the following research questions:

1. What are the characteristics of a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

2. What is the meaning in life for a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

3. What is the psychological well-being of a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

4. What is the reported level of caregiver burden of a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

5. What are the relationships among selected caregiver characteristics, meaning, psychological well-being and

caregiver burden for a sample of informal caregivers of patients who have been institutionalized for Alzheimer disease?

The conceptual model for the investigation was based on the philosophy of existentialism (Frankl, 1963). The model (see Figure 1, p. 67) depicted meaning and selected caregiver characteristics impacting on psychological well-being of the caregiver and this, in turn, influenced caregiver burden.

Characteristics of the Sample

Research question one will be answered by the following discussion in this section.

Sample

The response rate and selection method of potential subjects of this caregiving sample suggested that the sample may not be fully representative of caregivers of institutionalized Alzheimer patients. Qualitative data from potential respondents who declined to be interviewed suggested that health status of the caregiver or those who were truly burdened may have declined to participate in this investigation. Some comments from these potential respondents were:

> "I'm just not up to it."; "I don't want to discuss it with anyone else."; "I don't have the strength

to talk to you"; "It's just too hard to talk about."; and "I don't have the time."

Of the sample, the majority were female caregivers - 30 females and 15 males. This finding is consistent with other studies (Chenoweth & Spencer, 1986; George & Gwyther, 1986; Kinney & Stephens, 1989b; Miller et al., 1991; Pagel et al., 1985). Only one study by Kinney and Stephens (1989b) had a much higher percentage of female caregivers in their sample (81.7%).

The age range of caregivers in the sample was 27 - 92 years with a mean of 59 years. Study samples that have used spousal, adult child, and other caregivers (Cantor, 1983; George & Gwyther, 1986; Gilhooly, 1984; Kinney & Stephens, 1989b) have found similar results. As an example, George and Gwyther (1986), had an age range of 21 - 90, with a mean of 57 years. The majority of the sample were married (80%). This is comparable with caregiving literature (Cantor, 1983; Chenoweth & Spencer, 1986; Kiecolt-Glaser et al., 1987; Novak & Guest, 1989; Pett et al., 1988; Shanas, 1979; Staight & Harvey, 1990; Stone et al., 1987).

The care-recipients of the sample had been institutionalized for an average of 24 months. It was difficult to compare this characteristic of the sample as no other caregiving studies were found that used an exclusive sample of caregivers to the institutionalized. Several studies used a sample of

caregivers to institutionalized and noninstitutionalized care-recipients (Chenoweth & Spencer, 1986; Kiecolt-Glaser et al., 1987; Novak & Guest, 1989; Pett et al., 1988; Staight & Harvey, 1990). The only study which reported on length of institutionalization was Staight and Harvey (1990) who found the mean was 26.8 months. This is comparable to the present investigation findings.

Of the sample, 84.4% had completed high school or some form of post-secondary education. As 24% of the Newfoundland population have been described as illiterate (Council Ministers of Education of Canada, 1988), the education level of the sample was higher than the provincial average. Fairly well educated samples were characteristic of samples in the caregiving literature (George & Gwyther, 1986; Zarit, Todd & Zarit, 1986). The literature reported between 56% and 97% of the sample were well educated (Chenoweth & Spencer, 1986; Staight & Harvey, 1990). Only one Canadian study, conducted in Manitoba by Chappell (1991), addressed education level and 27% of the sample were reported to be high school graduates.

Income level has been reported to be positively related to education (Council Ministers of Education of Canada, 1988). Therefore, a study with a fairly well educated sample would expect the sample to have a higher level of income than the norm. In this investigation, the income level of the sample was comparable to samples used in other studies (Chenoweth &

Spencer, 1986; Gallagher et al., 1989; Kiecolt-Glaser et al., 1987; Pett et al., 1988; Zarit, Todd & Zarit, 1986). Two studies were found that used samples who were 'poor' or 'low to middle class income', Wilson (1990) and Stone et al. (1987), respectively.

The majority of respondents reported the quality of the relationship with the care-recipient as excellent. Although this finding could be indicative of reporting bias, it was supported in the literature by Cantor (1983) and Gilhooly (1984) who found that the respective samples rated relationship between caregiver and care-recipient as good to excellent.

The relationship between caregiver and care-recipient varied from spouse, adult child, and other (niece, sister, grand-daughter). In a study by Stones et al. (1987), the majority of caregivers were adult child (57.8%), followed by spouse (22.2%), and other (20%). This sample was nationally based in a North American population.

Length of illness ranged from 24 months to 20 years with a median of 72 months. Due to the paucity of literature using caregivers of institutionalized recipients, a comparison was difficult. Studies which used caregivers of both institutionalized and noninstitutionalized care-recipients reported a mean length of illness to be 65 months (Kiecolt-Glaser et al., 1987) and 67 months (Staight & Harvey, 1990). The sample

in this investigation was an exclusive sample of caregivers to institutionalized care-recipients and this may account for the slightly longer length of illness reported.

The majority of the sample (82%) reported adequacy of support to be good to excellent. The analog measure used in this investigation was not commonly used in caregiving literature. Several studies used instruments to measure support (Haley, Levine, Brown & Bartolucci, 1987), support in support groups for caregivers (Barnes, Raskind, Scott & Murphy, 1981), social network satisfaction (Pagel, Erdly & Becker, 1987), and, as such, no comparisons can be made with the present investigation.

An interesting finding in this investigation involved the membership and attendance of Alzheimer Support Groups. According to the results, these groups were not well utilized: 20% of the sample were members, yet only 4% attended the meetings. Whether the lack of membership is representative of caregivers of a recipient with Alzheimer disease or whether it is indicative of other factors such as issues of availability and accessibility remains to be seen, as only one study was found that addressed this issue. A study by Pratt, Schnall and Wright (1986) reported 61% of their sample to be members of an Alzheimer support group, but the study neglected to explain recruitment of the sample. Qualitative data in this investigation reflected Alzheimer support groups were not

meeting some of the caregivers needs. For example some of the sample related the following:

> "... my life is sad enough, I don't need to waste my time listening to other people complain..."; "...I went once, but I came away feeling worse than before..."; "...they didn't teil me anything I didn't already know..."; and "... the things that people talked about didn't apply to my situation...".

The average visit to the care-recipient occurred 12 times a month and lasted 1-2 hours. As this investigation was only the second to use an exclusive sample of caregivers to institutionalized Alzheimer care-recipients (the first being Novak & Guest, 1992), the visiting patterns of caregivers has not been well addressed in the caregiving literature. In order to enrich this data, examples of qualitative comments served to illuminate the importance of institutional visitation for the caregiver and reflected different institutional policies. Some of the sample made comments such as:

> "Just knowing that I can pop in at anytime to see Mom gives me more freedom."
>
> " We are not allowed to stay for meal times. I come back to my empty apartment and eat alone."
>
> "My visits revolve around meal times because I feel I'm doing something for Mom when I feed her."
>
> "Every day at 4pm I go to the home and M. (wife) and I have afternoon tea together - just like we always did."

"Visiting hours are not flexible, so some days I just can't get there ... then I feel really bad."

"The nurses are so kind. Every time I go they make sure that J. (husband) and I have some time alone together to sit and talk ... of course I do most of the talking ... I don't know if J. knows who I am or if he just thinks I'm a kind lady that sits and talks to him ... but I know."

"Not all visits go well, but the nurses help me through it."

"I'm glad to see Dad so well cared for ... every time I go see him, whatever the time of day, he's always well cared for."

Within Sample Variability

According to the findings from one-way analysis of variance by institution, the composite sample from three institutions was similar with respect to all variables under investigation, except income and life control. The difference in income can be traced to the origins of the institutions. Institution A was operated privately until a few years ago, whereas Institution C has been subsidized by the Government since its inception. The difference in life control between Institution B and Institution C may be a reflection of variation in visiting policy (ie. open visiting hours versus structured visiting hours). As no other differences were found, the sample was considered homogeneous in subsequent analyses.

Meaning

Research question two will be answered by the following discussion. It was reported on the Life Attitude Profile - Revised (LAP-R, Reker, 1992), measuring meaning, that the sample varied from the population norms reported by Reker (1992) on all subscales. In this investigation, the caregiving sample reported: less purpose in life; less coherence in life; less control in life; more apathy in life; less death acceptance; and less desire to accept new challenges than the population norm. It is suggested that the caregiving role, viewed in the literature as being an extreme stress in life, may precipitate meaningful changes in the caregiver's view of life. As length of illness impacted on more than one dimension of the meaning (purpose, life control, existential vacuum), it is suggested that changes in meaning occur over time. This would be consistent with the view that, although life attitudes are entrenched, an extreme stress in life has the power to influence and change them (Kahana et al., 1988). In the present investigation this sample did not report high levels of burden, yet it may be suggested that institutionalization may have forced the caregivers to face the inevitable course of events, alleviating uncertainty about outcomes. This may have allowed the caregivers to increase purpose, and life control. Apathy in life was also decreased

in the process. Although the length of illness was a powerful influence on the meaning for the sample, it was not the only caregiver characteristic to be related to meaning. In this investigation, it appeared that as the length of institutionalization increased, the sample became more in tune with self, others, and life in general, suggesting an adaptation to caregiving in the institutional environment. The caregiver's purpose was found to increase as the time spent at visits increased. This might imply that the visits became the caregiver's purpose in life.

Psychological Well-Being

Research question three will be answered by the following discussion. Psychological well-being of the sample (measured by the depression/happiness scale, Stones and Kozma, 1989) was slightly lower than the population norm in their study (Stones & Kozma). This identifies caregivers as reporting lower scores on psychological well-being than the general non-caregiving population. Based on the literature review, this was an expected finding. In this investigation, three characteristics of the caregiver were found to be related to higher levels of psychological well-being: adequacy of support, higher level of income, and higher level of education. This suggests that each of these items would give the

caregiver a greater resource base on which to draw during the caregiving experience, thereby increasing psychological well-being. In addition, a negative relationship between psychological well-being and age was found which demonstrated that the older caregiver reported lower levels of psychological well-being. This finding is consistent with research by Kinney and Stephens (1989b) who reported the older caregiver sample were significantly more depressed than a younger comparative sample. As well, this is supported by other research studies (Gallagher et al., 1989; Haley, Levine, Brown & Bartolucci, 1987; Kiecolt-Glaser et al., 1987). The relationship between length of illness and psychological well-being suggested that lower levels of psychological well-being were reported with time. This result is consistent with findings by Baillie et al. (1988) who reported caregiving for an extended time placed the caregivers for mentally impaired elders at a high risk for depression. It is suggested that the caregiver becomes worn over time.

Caregiver Burden

Research question four will be answered by the following discussion. The mean scores on caregiver burden for this sample was relatively low. According to the caregiving literature, caregiver burden, although present in caregivers

of institutionalized care-recipients, was generally lower than caregivers in the community (George & Gwyther, 1986; O'Connor et al., 1990; Pett et al., 1988; Staight & Harvey, 1990; Zarit et al., 1980). The instrument that was used to measure caregiver burden (Caregiver Burden Inventory, Novak & Guest, 1989) was multidimensional, therefore the profile of the sample's caregiver burden will follow.

Developmental burden was the highest, followed by time dependence, physical, social, emotional. Comparisons in the literature were few, as caregiver burden profiles are relatively new. Developmental burden had the highest mean scores of the caregiver burden subscales. This finding was consistent with a recent study by Novak and Guest (1992). A study by Cantor (1983) ranked emotional burden as the most problematic for caregivers to the frail elderly at home. George and Gwyther (1986) reported emotional and social burden to be the hardest for caregivers of institutionalized care-recipients. Considering the different methodologies, it is possible that conceptual differences between instruments used in the different research studies may account for the different findings.

Time dependence burden reported the next highest mean scores. Based on the literature review, this was unexpected. For example, Staight and Harvey (1990) reported that time constraints differed between caregivers of institutionalized

versus noninstitutionalized recipients: the caregivers of institutionalized care-recipients reported more time for themselves. Yet, when you examine the questions in the time dependence burden subscale, an explanation unfolds. For example, 'My care receiver is dependent on me' and 'I have to watch over my care receiver constantly' may have been interpreted by the respondents in a protective sense and not a physical time sense. If this was the case, the researcher would like to suggest that time dependence burden is actually a misnomer and reflects the protective element of caregiving identified by Bowers (1987).

The small amount of reported emotional burden was also a surprise. Some qualitative comments from the recipients may shed some light on the findings. Some of the sample commented:

> "When I see H. (spouse) so well cared for and I think of how distressing it used to be, I feel better ..."
>
> " It's hard to see Mom there, but we couldn't handle it at home ..."
> "... I feel so relieved that he's here ..."
>
> "... if you had asked me these questions before Dad went in the home, the answers would have been entirely different ..."
>
> "compared to before, life is so much easier now ..."

These comments demonstrate that the caregivers used the

distress of the past as the criterion for their responses. The emotional distress of the pre-institutionalization period was so intense that the post-institutionalization distress was very little by comparison.

In this investigation, length of illness is a very influential variable for this sample of caregivers, affecting three domains of burden (developmental, physical, and social) simultaneously. This finding supported a cumulative nature of the effects of caregiving suggested by Johnson (1983). The results found a high level of income was associated with a low level of social burden. This suggested that income was a resource for the caregiver. Perceived adequacy of support decreased the effects of physical and social burden. Other researchers using uni-dimensional instruments have found similar results (Zarit, 1980). Age was related to burden, specifically developmental and emotional burden, and they were found to increase simultaneously. Therefore, the older caregiver experienced the highest level of burden. This was contrary to findings by Barusch and Spaid (1989) and Pruchno and Resch (1989) who reported burden was highest for the younger caregiver. The investigator would like to suggest two possible explanations for the findings in this investigation: (a) strong family relationships in the Newfoundland population increase younger caregivers acceptance of caregiving; and (b) institutionalization, which changes the context of caregiving,

allows the younger caregiver to get on with his/her busy life, whereas the older, usually spousal, caregiver experiences a profound loss in his/her partner in his/her activities of daily living and a continued tie to caregiving via visiting.

Relationships Among Selected Caregiver Characteristics, Meaning, Psychological Well-Being, and Caregiver Burden

In order to answer the research question five regarding the relationships among selected caregiver characteristics, meaning, psychological well-being and caregiver burden, a correlational matrix was created. Once relationships had been established, the significant variables were entered in stepwise multiple regression by (a) caregiver burden, and (b) psychological well-being. This step of the analysis was an exploration of causal pathways in the conceptual model. The relationships among the major variables (meaning, psychological well-being, caregiver burden) will be discussed in the following sections to afford a comprehensive view. The following sections are: (a) relationship between meaning and psychological well-being; (b) relationship between psychological well-being and caregiver burden; (c) relationship between meaning and caregiver burden; (d) exploration of causal pathways; and (e) predictive model.

Relationship Between Meaning and Psychological Well-Being

The results indicated meaning was related to psychological well-being. In this investigation, as the purpose became more intense, the caregiver was at risk for decreasing psychological well being. It could be speculated that a caregiver focusing solely on caregiving as the reason for existence, would have decreased psychological well-being. Yet, in this study, an individual needs to have diverse interests in his/her life in order to maintain a healthy perspective on caregiving. This is in contrast to Frankl's philosophy which would say that purpose would be the strongest influence within an individual.

Relationships Between Psychological Well-Being and Caregiver Burden

A strong relationship between psychological well-being and caregiver burden for all subscales, except time dependence burden was reported in the results. As each dimension of burden increased, the level of psychological well-being in the caregiver decreased. This finding was consistent with the caregiving literature (Pruchno et al., 1990). Furthermore this investigation found a relationship in all domains of caregiver burden, except time dependence burden. The lack of

a relationship between time dependence burden and psychological well-being warrants discussion. This domain of burden is, in the investigator's opinion, the least applicable to caregivers for an institutionalized care-recipient. Although this investigation did not compare spousal/non-spousal caregivers, it is possible that the two categories of caregiver may express time dependence burden quite differently after insti-tutionalization. The items refer to many duties that are assumed by formal caregivers within the institution. For example, helping with many basic functions and performing daily tasks. Therefore, the results may be reporting a reflection of the effects of institutionalization on the caregiver's daily routine.

Relationship Between Meaning and Caregiver Burden

On analysis of the results, three dimensions of the meaning were positively related to caregiver burden. They were: Purpose, Life Control, and Existential Vacuum. An interpretation of these findings suggests that he/she could become consumed with the experience. According to previous results, meaning was derived over time, with increased time spent at visits indicating increasing purpose.

Exploration of Causal Pathways

In this investigation, the only predictor of caregiver burden was psychological well-being. The next logical step was to identify the variable/variables which predicted psychological well-being. As reported in the results, one's individual purpose was the best predictor of psychological well-being. The next major influence was existential vacuum (frustrated "will to meaning"). Other variables to enter the regression equation, in order, were age, length of illness, number of visits, relationship to care-recipient. No other variables reached statistical significance. These six variables explained 78.7% of the psychological well-being in the sample. Although the literature review revealed no previous testing of this particular model, these results indicate that assessment of these six factors in caregivers of the institutionalized Alzheimer patient would enable nurses to determine the risk of decreased psychological well-being. Caregiver interventions which focus on the predictors of the mediating variable in caregiver burden would, indirectly, meet the caregiver's needs. This finding has major implications for health care professionals, especially nurses who have a greater access to caregivers of institutionalized Alzheimer patients.

Predictive Model

The predictive model (see Figure 2, page 105), based on the preceding results, suggested a linear relationship between the three major variables: meaning, psychological well-being, and caregiver burden. Four caregiver characteristics were also predictive of psychological well-being: age, length of illness, number of visits, and relationship to care-recipient, respectively. The predictive model presents a comprehensive view of the relationships among the variables in the investigation. The variables from the regression analysis are prioritized by order of weight when more than one variable entered the equation. According to these results, psychological well-being plays a mediating role between meaning and caregiver burden. It suggests that nurses may be able to reduce a caregiver's burden by enabling him/her to maintain high levels of psychological well-being. This is the initial testing of this particular model, therefore further research in indicated.

Summary of Discussion

In summary, this chapter has discussed the results of the investigation. It has: (a) described a sample of informal caregivers whose recipient of care was an institutionalized Alzheimer patient; and (b) explored the relationships among

meaning, psychological well-being, and caregiver burden. Together, a comprehensive view of this sample of informal caregivers whose recipient of care is an institutionalized Alzheimer patient has been presented. Identification of the predictor of caregiver burden (psychological well-being) will help to focus health care professionals, particularly nurses, on the assessment of caregiver burden in caregivers.

CHAPTER VI

Summary, Implications, and Recommendations

Summary

The purpose of this investigation was to: (a) to describe a sample of informal caregivers whose recipient of care was an institutionalized Alzheimer patient; and (b) to explore the relationships between meaning, psychological well-being, and caregiver burden for this sample. The investigation used a sample of caregivers of patients who have been institutionalized for Alzheimer disease (n=45). Data was collected for the descriptive, exploratory investigation by at-home interviews. The major variables were: meaning, psychological well-being, and caregiver burden and they were measured by Life Attitude Profile - Revised, Memorial University of Newfoundland Scale of Happiness, Caregiver Burden Inventory, respectively. The statistical analyses described the sample and revealed relationships among the variables. This resulted in a model depicting these relationships. This model will add to the increasing body of knowledge on caregiver burden, lending insight into this phenomenon. It may facilitate health care professionals in the formulation of interventions that are congruent to the caregiver's needs.

Psychological well-being was identified as the only

predictor of caregiver burden. Individual variations in psychological well-being were recognized. As well, this investigation identified meaning as an influence in these individual variations. Furthermore, this investigation verified individual meaning as a predictor of psychological well-being. When caregiving becomes the all-consuming purpose in the caregiver's life, everything revolves around the experience and depression is inevitable. Several other variables influenced psychological well-being. They were: age, length of the caregiving experience, number of visits, and relationship to care-recipient. Length of caregiving was a very influential variable in this investigation. The author suggests that caregivers of the institutionalized Alzheimer recipient may become worn over time. The explanation may lie in the progressive and irreversible nature of this disease. Seeing one's family member gradually reduced to someone who is not recognizable, must be an agonizing experience. This variable cannot be altered for the caregiver. The number of visits was a predictor of psychological well-being. As the number of visits increased, burden increased. This may be the one factor influencing psychological well-being that is observable. Relationship to the care-recipient was the final variable that was predictive of psychological well-being, but it is unalterable.

This investigation confirmed an indirect relationship

between meaning and caregiver burden, with psychological well-being playing the mediating role. In this investigation, length of illness impacted on meaning, psychological well-being, and caregiver burden. This finding may be attributed to the fact that a longer length of illness was reported by the sample than in other studies. Implications and recommendations for nursing practice, nursing education, and nursing research follow.

Implications for Nursing Practice

It must be acknowledged that implications for nursing practice are based on the model, which suggests that alteration of psychological well-being will alleviate caregiver burden. The nurse has more day-to-day contact with caregivers of institutionalized care-recipients than any other health care professional. He/she is in a position to establish a therapeutic rapport with the caregiver and assess his/her response to the caregiving role. It is imperative for nurses to take an active role with caregivers. The role of the nurse is to assist caregivers, provide guidance, direction, education, and support. The nurse must be aware of the factors that impact on caregiver burden and identify caregivers who may be at risk for high levels of caregiver burden. The results of the investigation indicate that individual meaning,

age, length of illness, number of visits, and relationship to care-recipient influence psychological well-being of the caregiver. These factors must be assessed in order to identify the "at risk" caregiver. The nurse must consider how the caregiver views the caregiving experience, be cognizant of visiting patterns, and collect information regarding length of illness and relationship to care-recipient. If the nurse identifies a caregiver who needs individual assistance, he/she would give individual counselling to the caregiver and focus on helping the caregiver identify his/her personal meaning of the experience. Ultimately, this would enable him/her to put the experience in focus with the other dimension in his/her life.

It was found that Alzheimer Support Groups were not well utilized. This suggested that they need to be reviewed. A comprehensive needs assessment might be conducted for Alzheimer Support Groups. The results would be evaluated to ensure they are meeting the needs of caregivers.

In summary, the nursing population must: (a) acknowledge the complexity of caregiver burden; (b) take an active role with caregivers; (c) identify caregivers who are "at risk" for high levels of burden; and (d) have a resource person to assist caregivers with high caregiver burden levels.

Implications for Nursing Education

The numbers of elderly are increasing in our society and this brings about an increase in diseases that are prevalent in the elderly such as, Alzheimer disease. Consequently, nurses will be in contact with more caregivers of care-recipients with Alzheimer disease than ever before. In order to maintain the provision of quality care to the public, nursing education must prepare its nurses to meet the challenge.

Nursing curriculums must incorporate gerontology and gerontics in order to facilitate the student's understanding of the care of the aged client. Beside the physiological and psychological changes in aging and nursing care of the aged, the curriculum should include the concept of caregiver burden. This would increase the student's awareness of the possible consequences of caregiving, such as: (a) positive and negative aspects of caregiving; (b) impact of individual meaning on caregiver burden; (c) potential for depression among the caregiving population; (d) predictors of psychological well-being; and (e) the reality of caregiver burden continuing after institutionalization of the care-recipient. All nurses should become aware of the impact of caregiving and interventions that may decrease burden levels. For example, nurses should be aware that visiting patterns of the caregiver may be indicative of increased caregiver burden levels.

All nursing curriculums should ensure that basic communication courses include, at a minimum, fundamentals of interviewing and counselling. Graduate programs should include a compulsory course on advanced counselling and interviewing techniques. All nurses should be educated about the political process and policy making, so that he/she may become an advocate for the caregiver of an institutionalized Alzheimer patient and play an active in health care policy making. The actualization of these implications would ensure that the nurse is equipped to deal with the caregiver.

Implications for Nursing Research

The ideas for several research projects emerged from the present investigation. They are:

1. As no other caregiving studies were found which exclusively used a sample of caregivers for institutionalized care-recipients with Alzheimer disease, further research using other samples of caregivers to institutionalized care-recipients is suggested.

2. Replicate this nursing investigation using matched control groups (institutionalized versus noninstitutionalized).

3. Replicate this nursing investigation using a Newfoundland urban sample matched with another Canadian urban

sample.

4. Further nursing research regarding the visiting patterns of caregivers caring for an institutionalized care-recipient.

5. Further nursing research regarding meaning.

6. Nursing research exploring institutional visiting policy and its impact on caregiver burden.

7. Nursing research to identify the components of Alzheimer Support Groups which are most beneficial to caregivers of institutionalized Alzheimer patients.

8. Further nursing research differentiating between the needs of the caregiver of institutionalized versus noninstitutionalized care-recipients with Alzheimer disease.

9. Further testing of the new model is warranted.

10. Research needed to study the perceptions of the caregiving role by spouse versus children.

In conclusion, this chapter has briefly highlighted the investigation, identified implications for nursing practice and nursing education, and recommended topics for further nursing research. These potential nursing studies would add to the body of knowledge on caregiver burden and increase the understanding of this complex phenomenon. The results would facilitate nurses' comprehension of caregiver burden, enabling them to deal effectively with individuals experiencing the impact of caregiving.

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APPENDIX A
Letter to Facility

8 Hunt Place
St. John's, Nfld.

Date

Administrator
Name of Institution
Address
St. John's, Nfld.

Dear Sir/Madam:

As a follow-up to the informal meeting on date, I would like to formally invite this facility to participate in a nursing research study. The research will be conducted by Kathryn Lono, a graduate student who is working towards her Master's in Nursing at Memorial University of Newfoundland under the supervision of Kathryn Hustins, Assistant Professor. The research focuses upon the relationships between caregiver burden, meaning, experience, and psychological well-being for a sample of informal caregivers of the institutionalized Alzheimer patient. The facility would be asked to act as an intermediary between the researcher and the potential subjects. This intermediary role would involve: 1) The selection of the person who is noted as the emergency contact for the Alzheimer patient from the chart; and 2) sending a letter on behalf of the researcher inviting the person to voluntarily participate in the nursing research.

Enclosed is a copy of the letter to be sent to the potential subjects on behalf of the researcher and a copy of the research proposal for your ethical review committee. I await official confirmation of your intent to participate in the research.

If you have any questions or concerns, please contact me at the above address or telephone 739-8809.

Yours truly,

Kathryn Lono

APPENDIX B
Letter to Potential Subjects

Address of Institution
St. John's, Nfld.

Date

Dear 'Name of Potential Subject',

You are being invited to participate in a nursing research study. The purpose of this study is to gather information from family members who are caring for a relative in an institution. This will help nurses to understand your experience. If you agree to participate, you will be contacted by Kathryn Lono, a graduate nursing student of Memorial University of Newfoundland School of Nursing who will be conducting the nursing research study. Your participation will involve 1-2 hours of your time. You will be asked to sign a consent form, giving your permission to be in the study, and to complete three questionnaires.

Your participation in the study is voluntary and you may withdraw at any time, without any questions being asked. Your identity will be confidential and the results will be reported anonymously.

Please return the enclosed form in the self-addressed, stamped envelope, so that the nurse may contact you.

Yours truly,

The Institution

APPENDIX C
Consent Form

CONSENT TO PARTICIPATE IN RESEARCH STUDY

Title: A study of the relationships between caregiver burden, meaning, and psychological well-being of the caregiver.

Investigator: Kathryn Lono

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or to withdraw from this study at any time.

Confidentiality of information will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Purpose of Study

1. To address the meaning for the caregiver.
2. To address the impact of the caregiving experience on the caregiver.
3. To identify the factors which have the greatest influence on both the meaning and caregiver burden.

Description of Procedures and Tests

You will be required to complete three questionnaires.

Duration of Subjects Participation

The duration of your participation is limited to the time that it will take to complete the the questionnaires. This is estimated to be 1-1 1/2 hours.

Foreseeable Risks, Discomforts, or Inconveniences

Participation in this study involves no foreseeable risks. There is a 1-2 hour time factor involved in completing the questionnaires. There may be items in the questionnaire which cause the subject discomfort because of their personal nature. You are free to refrain from answering any questions, at any time.

Other Relevant Information

A brief summary of the results will be available to the participants upon request.

I, _____, the undersigned, agree to participate in the research study described above.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been offered to me.

_____ _____

(Signature of Participant) (Date)

_____

(Signature of Witness, optional)

To Be Signed by Investigator

To the best of my ability to the subject I have explained to the subject the nature of this research study. I have invited questions and provided answers. I believe that the subject fully understands the implication and voluntary nature of the study.

_____ _____ _____

(Signature of Investigator) (Date) (Phone Number)

_____ (optional, Witness)

APPENDIX D
Demographic Data

DEMOGRAPHIC DATA

Code Name:

Age:

Sex: Male Female

Marital Status: Single Married Separated Divorced

Length of time the care-recipient has been institutionalized:

Relationship to care-recipient:

Education Level:
- Less than Grade V
- Grade XII or Equivalent
- Post-Secondary

Length of Care-Recipient's Illness:

Circle the number which best describes your situation:

Quality of Relationship with Care-Recipient:

1	2	3	4	5
Poor				Excellent

Adequacy of Support for Caregiver:

1	2	3	4	5
Poor				Excellent

Are you a member of an Alzheimer support group?

Yes No

If yes, how often do you attend the meetings?

Always Sometimes Never

Income:	$10,000-$19,999	1
	$20,000-$29,999	2
	$30,000-$39,999	3
	$40,000-$49,999	4
	$50,000-$59,999	5
	$60,000 +	6

Number of visits per month to the care recipient:

Usual time spent at each visit:

What do you usually do during the visit?

Comments:

APPENDIX E
Life Attitude Profile - Revised (LAP-R)

LIFE ATTITUDE PROFILE-REVISED (LAP-R)

This questionnaire contains a number of statements related to opinions and feelings about yourself and life in general. Read each statement carefully, then indicate the extent to which you agree or disagree by circling one of the alternative categories provided. For example, if you **STRONGLY AGREE**, CIRCLE **SA** following the statement. If you **MODERATELY DISAGREE**, circle **MD**. If you are **UNDECIDED**, circle **U**. Try to use the undecided category sparingly.

SA	**A**	**MA**	**U**	**MD**	**D**	**SD**
Strongly Agree	Agree	Mod. Agree	Undecided	Mod. Disagree	Disagree	Strongly Disagree

1.	My past achievements have given my life meaning and purpose.	SA	A	MA	U	MD	D	SD
2.	In my life I have very clear goals and aims.	SA	A	MA	U	MD	D	SD
3.	I regard the opportunity to direct my life as very important.	SA	A	MA	U	MD	D	SD
4.	I seem to change my main objectives in life.	SA	A	MA	U	MD	D	SD
5.	I have discovered a satisfying life purpose.	SA	A	MA	U	MD	D	SD
6.	I feel that some element which I can't quite define is missing from my life.	SA	A	MA	U	MD	D	SD
7.	The meaning of life is evident in the world around us.	SA	A	MA	U	MD	D	SD

SA	A	MA	U	MD	D	SD
Strongly Agree	Agree	Mod. Agree	Undecided	Mod. Disagree	Disagree	Strongly Disagree

8.	I think I am generally much less concerned about death than those around me.	SA	A	MA	U	MD	D	SD
9.	I feel the lack of and a need to find a real meaning and purpose in my life.	SA	A	MA	U	MD	D	SD
10.	New and different things appeal to me.	SA	A	MA	U	MD	D	SD
11.	My accomplishments in life are largely determined by my own efforts.	SA	A	MA	U	MD	D	SD
12.	I have been aware of an all powerful and consuming purpose towards which my life has been directed.	SA	A	MA	U	MD	D	SD
13.	I try new activities or areas of interest and then these soon lose their attractiveness.	SA	A	MA	U	MD	D	SD
14.	I would enjoy breaking loose from the routine of life.	SA	A	MA	U	MD	D	SD
15.	Death makes little difference to me one way or another.	SA	A	MA	U	MD	D	SD
16.	I have a philosophy of life that gives my existence significance.	SA	A	MA	U	MD	D	SD
17.	I determine what happens in my life.	SA	A	MA	U	MD	D	SD

SA	A	MA	U	MD	D	SD
Strongly Agree	Agree	Mod. Agree	Undecided	Mod. Disagree	Disagree	Strongly Disagree

18.	Basically, I am living the kind of life I want to live.	SA	A	MA	U	MD	D	SD
19.	Concerning my freedom to make my choice, I believe I am absolutely free to make all life choices.	SA	A	MA	U	MD	D	SD
20.	I have experienced the feeling that while I am destined to accomplish something important, I cannot put my finger on just what it is.	SA	A	MA	U	MD	D	SD
21.	I am restless.	SA	A	MA	U	MD	D	SD
22.	Even though death awaits me, I am not concerned about it.	SA	A	MA	U	MD	D	SD
23.	It is possible for me to live my life in terms of what I want to do.	SA	A	MA	U	MD	D	SD
24.	I feel the need for adventure and "new worlds to conquer".	SA	A	MA	U	MD	D	SD
25.	I would neither fear death nor welcome it.	SA	A	MA	U	MD	D	SD
26.	I know where my life is going in the future.	SA	A	MA	U	MD	D	SD
27.	In thinking of my life, I see a reason for my being here.	SA	A	MA	U	MD	D	SD

SA	A	MA	U	MD	D	SD
Strongly Agree	Agree	Mod. Agree	Undecided	Mod. Disagree	Disagree	Strongly Disagree

28.	Since death is a natural aspect of life, there is no sense worrying about it.	SA	A	MA	U	MD	D	SD
29.	I have a framework that allows me to understand or make sense of my life.	SA	A	MA	U	MD	D	SD
30.	My life is in my hands and I am in control of it.	SA	A	MA	U	MD	D	SD
31.	In achieving life's goals, I have felt completely fulfilled.	SA	A	MA	U	MD	D	SD
32.	Some people are very frightened of death, but I am not.	SA	A	MA	U	MD	D	SD
33.	I daydream of finding a new place for my life and a new identity.	SA	A	MA	U	MD	D	SD
34.	A new challenge in my life would appeal to me now.	SA	A	MA	U	MD	D	SD
35.	I have the sense that parts of my life fit together into a unified pattern.	SA	A	MA	U	MD	D	SD
36.	I hope for something exciting in the future.	SA	A	MA	U	MD	D	SD
37.	I have a mission in life that gives me a sense of direction.	SA	A	MA	U	MD	D	SD
38.	I have a clear understanding of the ultimate meaning of life.	SA	A	MA	U	MD	D	SD

SA	A	MA	U	MD	D	SD
Strongly Agree	Agree	Mod. Agree	Undecided	Mod. Disagree	Disagree	Strongly Disagree

39. When it comes to important life matters, I make my own decisions. SA A MA U MD D SD

40. I find myself withdrawing from life with an "I don't care" attitude. SA A MA U MD D SD

41. I am eager to get more out of life than I have so far. SA A MA U MD D SD

42. Life to me seems boring and uneventful. SA A MA U MD D SD

43. I am determined to achieve new goals in the future. SA A MA U MD D SD

44. The thought of death seldom enters my mind. SA A MA U MD D SD

45. I accept personal responsibility for the choices I have made in my life. SA A MA U MD D SD

46. My personal existence is orderly and coherent. SA A MA U MD D SD

47. I accept death as another life experience. SA A MA U MD D SD

48. My life is running over with exciting good things. SA A MA U MD D SD

APPENDIX F
Caregiver Burden Inventory (CBI)

CAREGIVER BURDEN INVENTORY
(Novak and Guest, 1989)

Now we would like to know how you see your experience as a caregiver and what your feelings are about giving care. Think of your experiences as a family caregiver. How well does each of the following statements describe your experience in caring for your care receiver in the past month?

	0 Not at all Descriptive	1 Slightly	2 Moderately Descriptive	3 Quite	4 Very Descriptive
1.	My care receiver needs my help to perform many daily tasks.	0	1	2	3 4
2.	My care receiver is dependent on me.	0	1	2	3 4
3.	I have to watch my care receiver constantly.	0	1	2	3 4
4.	I have to help my care receiver with many basic functions.	0	1	2	3 4
5.	I don't have a minute's break from my caregiving chores.	0	1	2	3 4
6.	I feel that I am missing out on life.	0	1	2	3 4
7.	I wish I could escape from this situation.	0	1	2	3 4
8.	My social life has suffered.	0	1	2	3 4
9.	I feel emotionally drained due to caring for my care receiver.	0	1	2	3 4
10.	I expected that things would be different at this point in my life.	0	1	2	3 4

	0 Not at all Descriptive	1 Slightly	2 Moderately Descriptive	3 Quite	4 Very Descriptive
11.	I'm not getting enough sleep.	0	1	2	3 4
12.	My health has suffered.	0	1	2	3 4
13.	Caregiving has made me physically sick.	0	1	2	3 4
14.	I'm physically tired.	0	1	2	3 4
15.	I don't get along with other family members as well as I used to.	0	1	2	3 4
16.	My caregiving efforts aren't appreciated by others in my family.	0	1	2	3 4
17.	I've had problems with my marriage.	0	1	2	3 4
18.	I don't do as good a job at work as I used to.	0	1	2	3 4
19.	I feel resentful of other relatives who could but do not help.	0	1	2	3 4
20.	I feel embarrassed over my care receiver's behaviour.	0	1	2	3 4
21.	I feel ashamed of my care receiver.	0	1	2	3 4
22.	I resent my care receiver.	0	1	2	3 4
23.	I feel uncomfortable when I have friends over.	0	1	2	3 4
24.	I feel angry about my interactions with my care receiver.	0	1	2	3 4

APPENDIX G
Memorial University of Newfoundland Scale of Happiness (MUNSH)

MEMORIAL UNIVERSITY SCALE OF HAPPINESS

(Stones & Kozma, 1989)

We would like to ask you some questions about how things have been going. Please answer "yes" if a statement is true for you and "no" if it does not apply to you. In the past months have you been feeling:

1.	On top of the world?	Yes	No
2.	In high spirits?	Yes	No
3.	Particularly content with your life?	Yes	No
4.	Lucky?	Yes	No
5.	Bored?	Yes	No
6.	Very lonely or remote from other people?	Yes	No
7.	Depressed or very unhappy?	Yes	No
8	Flustered because you didn't know what wasexpected of you?	Yes	No
9.	Bitter about the way your life has turned out?	Yes	No
10.	Generally satisfied with the way your life has turned out?	Yes	No

The next 14 questions have to do with more general life experiences.

11.	This is the dreariest time of my life.	Yes	No
12.	I am just as happy as when I was younger.	Yes	No
13.	Most of the things I do are boring or monotonous.	Yes	No

14.	The things I do are as interesting to me as they ever were.	Yes:	No
15.	As I look back on my life, I am fairly well satisfied.	Yes:	No
16.	Things are getting worse as I get older.	Yes:	No
17.	Do you feel lonely?	Yes:	No
18.	Little things bother me more this year.	Yes:	No
19.	If you could live where you wanted, would you live here?	Yes:	No
20.	I sometimes feel that life isn't worth living.	Yes:	No
21.	I am as happy now as I was when I was younger.	Yes:	No
22.	Life is hard for me most of the time.	Yes:	No
23.	Are you satisfied with your life today?	Yes:	No
24.	My health is the same or better than most people's my age.	Yes:	No

APPENDIX H
Permission to Use Life Attitude Profile - Revised (LAP-R)

Department of Psychology
Trent University
Peterborough, Ontario
Canada K9J 7B8

July 7, 1992

Ms. Kathryn Ionn
8 Hunt Place
St. John's, NF
A1B 2J9

Dear Kathryn:

Permission is granted to use the IAP R in your Ph.D. dissertation. Enclosed is a revised manual of the IAP R with full documentation on its psychometric properties.

All the best.

Sincerely,

Gary T. Reker, Ph.D.
Professor

GTR:dp
Encl.

APPENDIX I
Permission to Use Memorial University Scale of Happiness (MUNSH)

DATE : Aug 16, 1993

TO : Cathy Lono
:

FROM : Michael Stones, MUN Gerontology Centre, MUN
: St. John's, Newfoundland, Canada A1B 3X9

FAX PHONE : (709) 737 4000 or (709) 737 4510

VOICE PHONE : (709) 895 2132 (home); (709) 737 4381 (work)

MESSAGE : Permission gladly granted to use the MUNSH
: in your thesis research.
:

APPENDIX J
Permission to Use Caregiver Burden Inventory (CBI)

THE UNIVERSITY OF MANITOBA CONTINUING EDUCATION DIVISION Winnipeg, Manitoba
Canada R3T 2N2
Tel (204) 474-8821
FAX (204) 275-5865

June 10, 1992

Ms. Kathryn Lono
8 Hunt Place
St. John's, Nfld.
A1B 2J9

Dear Ms. Lono:

Enclosed is the Caregiver Burden Inventory and the method used for scoring responses.

You may use the CBI in your thesis proposal.

Sincerely,

Mark Novak, Ph.D.
Associate Dean (Academic)

MN/pp
encl.

APPENDIX K
Oneway Analysis of Variance for Caregiver Characteristics, Meaning, Psychological Well-Being, Caregiver Burden by Institution

Oneway Analysis of Variance for Caregiver Characteristics, Meaning, Psychological Wel -Being, Caregiver Burden by Institution

Variable	P Value
Age	.9306
Length of Institutionalization	.7234
Length of Care	.9867
Education	.4673
Adequacy of Support	.2627
Income	.005**
Number of Visits	.8118
Quality of Relationship	.0581
Alzheimer Support Group Member	.5922
Caregiver Burden	.2544
Psychological Well-Being	.8583
Purpose	.1562
Coherence	.5499
Life Control	.0317
Death Acceptance	.1068
Existential Vaccuum	.1510
Goal Seeking	.0722

** $p < .01$

APPENDIX L
Frequency Distribution of the Life Attitude Profile - Revised (LAP-R) Scores of the Sample by Subscale (n=45)

Frequency Distribution of the Life Attitude Profile - Revised (LAP-R) Scores of the Sample by Subscale (n=45)

Subscale	Scores	Frequency
Purpose (PU)	11.00	1
	12.00	1
	14.00	1
	16.00	4
	17.00	6
	18.00	2
	19.00	1
	21.00	7
	22.00	3
	23.00	5
	25.00	1
	26.00	3
	27.00	1
	28.00	1
	31.00	1
	32.00	2
	35.00	1
	36.00	1
	37.00	1
	38.00	1
	39.00	1
Coherence (CO)	12.00	2
	13.00	1
	14.00	4
	15.00	2
	16.00	3
	17.00	3
	18.00	2
	19.00	2
	20.00	2
	21.00	6
	22.00	4
	23.00	1
	24.00	3
	25.00	1
	26.00	3
	27.00	2
	28.00	1
	29.00	1
	34.00	1
	38.00	1

Subscale	Scores	Frequency
Life Control (LC)	10.00	4
	11.00	1
	12.00	2
	13.00	2
	14.00	3
	15.00	2
	16.00	3
	18.00	2
	19.00	1
	20.00	5
	21.00	5
	22.00	2
	23.00	7
	26.00	1
	27.00	2
	31.00	1
	32.00	1
	36.00	1
Death Acceptance (DA)	8.00	3
	9.00	1
	11.00	3
	12.00	1
	14.00	1
	15.00	3
	16.00	4
	17.00	2
	18.00	1
	19.00	3
	20.00	3
	22.00	2
	23.00	1
	24.00	2
	25.00	1
	26.00	3
	27.00	1
	29.00	1
	31.00	3
	33.00	1
	35.00	1
	39.00	1
	40.00	2
	46.00	1

Subscale	Scores	Frequency
Existential Vaccuum (EV)	19.00	2
	23.00	1
	27.00	1
	28.00	2
	30.00	1
	32.00	1
	33.00	3
	34.00	4
	36.00	1
	38.00	2
	41.00	4
	42.00	1
	43 00	3
	44.00	4
	45.00	6
	46.00	1
	47.00	1
	48.00	2
	49.00	2
	51.00	3
Goal Seeking (GS)	10.00	1
	13.00	1
	14.00	1
	17.00	2
	19.00	1
	20.00	1
	21.00	1
	22.00	2
	23.00	1
	24.00	2
	25.00	3
	26.00	2
	27.00	2
	28.00	4
	30.00	1
	31.00	2
	32.00	1
	33.00	2
	34.00	2
	36.00	1
	37.00	2
	38.00	4
	41.00	3
	46.00	2
	47.00	1

APPENDIX M
Frequency Distribution of Memorial University of Newfoundland Scale of Happiness Scores (n=45)

Frequency Distribution on Memorial University of Newfoundland Scale of Happiness Scores (n=45)

MUNSH Scores	Frequency
-16.00	1
-14.00	1
-12.00	1
-10.00	1
-6.00	1
2.00	1
4.00	3
6.00	1
8.00	3
10.00	2
12.00	1
14.00	3
16.00	4
18.00	8
20.00	9
22.00	2
24.00	3

APPENDIX N
Frequency Distribution of Total Scores
and Subscales of Caregiver Burden Inventory Scores
(CBI) (n=45)

Frequency Distribution of Total Scores and Subscales of Caregiver Burden Inventory Scores (CBI) (n=45)

Item	Scores	Frequency
Total Scores of the CBI	0.00	1
	1.00	1
	2.00	1
	6.00	1
	7.00	2
	10.00	2
	11.00	4
	12.00	4
	13.00	1
	15.00	4
	16.00	1
	18.00	2
	19.00	2
	20.00	1
	23.00	1
	25.00	1
	27.00	2
	29.00	1
	33.00	2
	35.00	1
	36.00	1
	37.00	1
	38.00	1
	39.00	1
	42.00	1
	43.00	1
	44.00	1
	45.00	1
	46.00	1
	53.00	1
Time Burden	0.00	5
	1.00	3
	2.00	2
	3.00	4
	4.00	6
	5.00	3
	6.00	1
	7.00	4
	8.00	4

Item	Scores	Frequency
Time Burden (continued)	9.00	2
	10.00	2
	11.00	2
	12.00	1
	13.00	2
	14.00	3
	16.00	1
Developmental Burden	0.00	5
	1.00	2
	2.00	2
	3.00	4
	4.00	2
	5.00	4
	6.00	5
	7.00	1
	8.00	5
	9.00	1
	10.00	3
	11.00	2
	13.00	2
	14.00	1
	16.00	2
	17.00	1
	18.00	1
	19.00	1
	20.00	1
Physical Burden	0.00	14
	1.25	11
	2.50	4
	3.75	1
	5.00	3
	6.25	3
	7.50	1
	11.25	1
	12.50	1
	13.75	1
	15.00	4
	18.75	1

Item	Scores	Frequency
Social Burden	0.00	12
	1.00	4
	2.00	6
	3.00	5
	4.00	6
	5.00	1
	6.00	5
	8.00	1
	9.00	1
	10.00	1
	11.00	1
	13.00	2
Emotional Burden	0.00	19
	1.00	9
	2.00	11
	4.00	1
	5.00	2
	6.00	1
	7.00	1
	16.00	1